

Transitions experienced by mothers of children/adolescents with sickle cell disease in the context of the COVID-19 pandemic



Transições vivenciadas por mães de crianças/adolescentes com doença falciforme no contexto da pandemia da COVID-19

Transiciones vividas por madres de niños/adolescentes con enfermedad de células falciformes en el contexto de la pandemia de COVID-19

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ABSTRACT

Objective: To analyze the transitions experienced by mothers and children/adolescents with sickle cell disease after the emergence of the COVID-19 pandemic.

Method: A qualitative study involving 19 mothers of children and adolescents with sickle cell disease. Data were obtained through semi-structured interviews via WhatsApp, followed by Thematic Analysis and Descending Hierarchical Classification with the help of Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires and interpreted in the light of Afaf Meleis' Transition Theory.

Results: Support from family members for displacement; mothers' adherence to the routine of daily stimuli and physical exercises favored healthy transitions; lack of remote health care; low socioeconomic resources; interruption of the physiotherapy service; and maternal overload favor unhealthy transitions.

Final considerations: Efforts/movements by mothers ensure the healthy transition of children/adolescents with sickle cell disease during the pandemic, while supporting their unhealthy transition.

Keywords: COVID-19. Chronic disease. Anemia, sickle cell. Nursing. Family.

RESUMO

Objetivo: Analisar as transições vivenciadas por mães de crianças/adolescentes com doença falciforme após o surgimento da pandemia da COVID-19.

Método: Estudo qualitativo, envolveu 19 mães de crianças e adolescentes com doença falciforme. Os dados foram obtidos mediante entrevistas semiestruturadas via WhatsApp, seguidas de Análise Temática e Classificação Hierárquica Descendente com auxílio do Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires e interpretados à luz da Teoria de Transições de Afaf Meleis.

Resultados: Apoio dos familiares para deslocamento; adesão das mães à rotina de estímulos diários e exercícios físicos favoreceram as transições saudáveis; inexistência de atendimento de saúde remoto; baixos recursos socioeconômicos; interrupção do serviço de fisioterapia; e sobrecarga materna favorecem as transições insalubres.

Considerações finais: Esforços/movimentos das mães asseguraram a transição saudável de crianças/adolescentes com doença falciforme durante a pandemia, ao mesmo tempo que corroborou para a transição insalubre das mesmas.

Palavras-chave: COVID-19. Doença crônica. Anemia falciforme. Enfermagem. Família.

RESUMEN

Objetivo: Analizar las transiciones vividas por madres y niños/adolescentes con enfermedad de células falciformes después del surgimiento de la pandemia de COVID-19.

Método: Estudio cualitativo en el que participaron 19 madres de niños y adolescentes con enfermedad de células falciformes. Los datos se obtuvieron a través de entrevistas semiestruturadas vía WhatsApp, seguidas de Análisis Temático y Clasificación Jerárquica Descendente con la ayuda de Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires interpretadas a la luz de la Teoría de la Transición de Afaf Meleis. Resultados: Apoyo de familiares por desplazamiento; la adherencia de las madres a la rutina de estímulos diarios y ejercicios físicos favoreció las transiciones saludables; falta de atención médica remota; bajos recursos socioeconómicos; interrupción del servicio de fisioterapia; y la sobrecarga materna favorecen las transiciones poco saludables.

Consideraciones finales: Los esfuerzos/movimientos de las madres aseguran la transición saludable de los niños/adolescentes con enfermedades de células falciformes durante la pandemia, al mismo tiempo que apoyan su transición no saludable.

Palabras clave: COVID-19. Enfermedad crónica. Anemia de células falciformes. Enfermería. Familia.

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■ INTRODUCTION

Despite the high number of people infected by COVID-19 and with mild or non-existent symptoms⁽¹⁾, individuals with a previous disease may have complications that require hospitalization and, often, intensive care, such as those with Sickle Cell Disease (SCD). SCD, the most common genetic condition worldwide, concerns a set of hemoglobinopathies with great clinical variability, characterized by the presence of hemoglobin S. Clinical variability explains the fact that some people have severe conditions and are subject to numerous complications and frequent hospitalizations, while others have a more benign evolution, in some cases almost asymptomatic⁽²⁾.

Hemolytic anemia, vaso-occlusive crises, endothelial damage to various organs, release of inflammatory cytokines and chemokines, tissue and coagulation factors make up the complex pathophysiology of SCD⁽³⁾ and, therefore, people with SCD tend to be more severely affected by SCD infection. COVID-19 when compared to the general population, due to their chronic condition and other associated vulnerabilities⁽⁴⁾. Furthermore, the fact that SCD affects the immune system and increases the chances of developing respiratory infections placed children and adolescents with SCD in the "high risk" category for COVID-19.

Due to the suspension of many health services (mainly elective ones), the COVID-19 pandemic led to a reduction or discontinuation in the monitoring of chronic diseases⁽⁵⁾ and worsened the social condition and the quality of life of vulnerable people, exacerbating the economic crisis and the difficulties in accessing healthcare services. Moreover, children and adolescents were also affected by the closure of schools, due to the suspension of food delivery and the non-availability of activities that are usually performed in the school environment⁽⁶⁾.

Relatives of people with chronic diseases were also affected by negative feelings, given the risks entailed by the vulnerability of the health conditions of these people. It should be mentioned that family members of individuals with chronic illnesses, who already experience symptoms of anxiety and depression, need additional emotional, psychological and spiritual support⁽⁷⁾.

All these social, economic and emotional processes are stressful factors for families, intensifying their vulnerability and demanding a process of structural reorganization. This makes a systemic understanding of family functioning necessary, given that families in extreme situations, with acute or chronic crises, are very impacted⁽⁸⁾. The COVID-19

pandemic has accelerated changes in the daily lives of the entire population, which generated transition processes.

When formulating her Theory of Transitions, nurse Afaf Ibrahim Meleis considers the transition a complex process that affects several dimensions, which can lead to changes in the course of life, health, relationships and the environment⁽⁹⁾. Transitions result from critical events and changes produced in individuals or environments, and may present single or multiple, sequential or simultaneous, related or unrelated patterns⁽¹⁰⁾.

Transitions are classified according to the nature of the way they affect people, namely: developmental, when referring to changes in the life cycle; situational, when related to situations that require role redefinitions; health-illness, which occurs when there is a change in health-illness status; and organizational, when it derives from changes in institutional environments⁽¹¹⁾.

Transitions can be defined as healthy – being related to the mastery of emotions, behaviors or signs associated with new roles – or unhealthy – when they move the individual towards their vulnerabilities, having the ability to resist new meanings. There is also role insufficiency, which is defined by the difficulty for the individual to play a role, when behavior and feelings fail to fulfill obligations or expectations⁽¹⁰⁾.

People's responses during the transition experience are influenced by their level of knowledge and skills for change, as well as their expectations in the face of the new situation⁽¹⁰⁾. As they grow up, children experience different transitions and significant events. Many of these events are common to most children and can usually be anticipated or expected, others can be unpredictable and unexpected. Chronic illness in children/adolescents with SCD requires them and their caregivers to learn different skills to deal with changes in roles, adapt to new social demands and, at the same time, face the onset of complications of the disease and learn to promote self-care⁽¹²⁾. In this regard, it is estimated that in a health emergency, the developmental transitions of children and adolescents, which already impose constant adaptations in the daily lives of mothers, add to the challenges of situational transitions. Thus, the following question is asked: "How did mothers of children/adolescents with SCD experience transitions in the face of the changes imposed by the pandemic on their daily lives?". From the need to know changes experienced in vulnerable groups to support the planning of care actions, this article aims to analyze the transitions experienced by mothers of children/adolescents with SCD after the emergence of the COVID-19 pandemic.

■ METHOD

This is a qualitative study in the light of Afaf Meleis Theory of Transitions, developed from March to April 2021 with 19 mothers of children/adolescents with SCD registered at the Municipal Reference Center for People with Sickle Cell Disease in Feira de Santana, Bahia. The mothers who participated in the study manage a group on the WhatsApp virtual social network, which aims to facilitate communication before and during the pandemic and also provides a support space for the demands of their children. Access to the WhatsApp group occurred through the intermediation of the researcher with the president of the Association of People with Sickle Cell Disease of Feira de Santana, the main manager of the group. The WhatsApp group consisted of 39 mothers of children/adolescents with SCD, but 20 mothers did not agree to participate in the study, allegedly due to lack of time.

The inclusion criterion was being the mother of a child/adolescent with SCD aged between 2 and 15 years old. The choice of this age group is due to the need to include children from preschool to adolescence, in order to analyze the transitions experienced by mothers with children in different stages and the different levels of dependence and support for disease control and self-care. Mothers who did not live with their children for at least five days a week were excluded. Theoretical saturation was adopted as a criterion for stopping the interviews. Saturation of themes was reached by the 16th interview. Thus, the team decided to carry out 3 more interviews and, when there was no emergence of new elements for the understanding of the phenomenon, data collection was discontinued in the 19th interview⁽¹³⁾.

To enable data collection and respect biosecurity measures during the pandemic, empirical data were produced through semi-structured interviews with the aid of the WhatsApp application. The audios obtained through conversation were recorded directly in the application. The justification for using this resource is that it facilitates communication with mothers with low educational level and who have difficulties in managing other digital platforms.

The interviews were guided through a semi-structured guide with closed-ended questions about the sociodemographic profile and open-ended questions triggered by the following guiding question: What were the changes that occurred in the daily lives of children/adolescents with SCD and their families after the onset of the AIDS pandemic? COVID-19?

For data collection, an initial contact was established with the mothers of children/adolescents with SCD who were in the group to explain the research and establish a relationship of trust. At this initial moment, an invitation was

made to the mothers to participate in the study through a voice message and information about the objectives, risks, benefits and relevance of the study was provided by reading, by audio, and the Free and Informed Consent Form, to obtain the acceptance of the family member to carry out the interview. To guarantee the anonymity of the study participants, they were identified by letter I followed by the number corresponding to the order of the interviews during the transcription and presentation of the results. The interviews lasted around 20 minutes.

The interviews were conducted by the first author of this study, a female nurse with a master degree in nursing. The main author had previous experience in collecting qualitative data and was familiar with the group of participants. The answers to the interviews were fully transcribed by the same author and submitted to textual analysis with the aid of the IRAMUTEQ software (*Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*) 0.7 alpha 2 regarding the Thematic Analysis (TA), with the aim of to analyze the transitions experienced by mothers of children/adolescents with sickle cell disease after the onset of the COVID-19 pandemic.

The textual corpus that was processed in IRAMUTEQ generated the Descending Hierarchical Classification (DHC). The DHC consists of a lexicographical analysis, through the context of a set of text segments, which allows the statistical processing of text information, grouping axes and hierarchical word classes according to frequency. To create a dictionary of words, the software uses the chi-square test (χ^2), which reveals the associative strength between words and their respective class⁽¹⁴⁾.

The DHC was used for textual analysis of the research. In this analysis text segments are classified according to their respective vocabularies through the text set to be analyzed. The set of these segments is divided according to the frequency of the reduced forms. The DHC is carried out in three steps: preparation and encoding of the initial text, descending hierarchical classification carried out by data processing, and the interpretation of the classes⁽¹⁴⁾.

Systematization of textual analysis (TA) in this research was performed in six phases, in which one phase does not necessarily precede the other: familiarization with the data; initial code generation; theme search; theme review; definition and naming of themes; and report production⁽¹⁵⁾. DHC findings were confronted with the core meanings and themes obtained through TA, which made it possible to name the DHC classes in line with the thematic categories.

The present study was approved by the Ethics and Research Committee of Universidade Estadual de Feira de Santana – under protocol no 4.351.453, CAAE no

36753420.2.0000.0053 –, complying with the ethical principles and recommendations of Resolutions no 466/2012 and CNS 510/2016, concerning research procedures at any stage in a virtual environment. After the completion of the study, the results were shared with the study participants, who agreed with them.

■ RESULTS

The study included 19 mothers of children/adolescents with SCD, aged 20-49 years and predominantly housewives. Among them, 17 reported that, until the time of the interview, none of their family members had tested positive for COVID-19. The ages of the children/adolescents with SCD whose mothers were interviewed are described in Chart 1.

The results are organized in DHC classes, visualized in Figure 1 and in the thematic categories shown below.

For the DHC, 19 text units (interviews) were processed in IRAMUTEQ, which divided the corpus into 301 text segments, containing 437 hepar (different) terms. With the use of 84.6% of the text segments, terms with a frequency greater than or equal to 30 were considered for analysis, according to the criterion established in the calculation of the chi-square (χ^2), that is, the χ^2 from 15, 61 with 1 degree of freedom is significant and reveals greater associative strength. From the CHD emerged the structure of the corpus represented by Figure 1, whose dendrogram allowed the observation of the description of each of the classes, composed by the titles and numbers of text segments that compose them, as well as the words of greater association with the corresponding class through chi-square (χ^2). The χ^2 indicates which words had a significance value less than or equal to 0.01.

In this figure class 1 (**Efforts/movements of mothers ensured the healthy transition of children/adolescents with SCD**) was the one with the greatest representation (weight) in the analyzed corpus, as the textual elements of this class are common to most participants. Class 3 (**Changes adopted by mothers guide the child/adolescent with SCD towards a healthy transition**) was the second

class with the highest representation, followed by Class 2 (**Overprotection to avoid catching COVID-19**) and Class 4 (**Social distancing required suspending medical appointments**). Class 5 (**Efforts by mothers to promote the healthy transition of their children corroborates their unhealthy transition**) had less representation.

The aforementioned classes constituted the representative empirical categories of the transitions experienced and explored in this research and were reordered to give more clarity to the investigated phenomenon.

Overprotection to avoid catching COVID-19

Realizing their children's vulnerability to acquiring infections, the mothers of children/adolescents with SCD mentioned that they were responsible for their protection, revealing concern, fear and despair with the possibility of contamination by the coronavirus, deciding to overprotect their children during the pandemic:

I feel quite responsible. Responsible because I know that she belongs to the risk group, that we have to be very careful, very careful with food, hygiene, everything. (I3)

As soon as the pandemic started, I stopped before everything stopped. I stopped sending her to school and I was really, really, really worried about it. At first, I was very desperate, I didn't want her to leave the house, I didn't want to get in touch with anyone. (I8)

Mothers of children/adolescents with SCD were afraid that their children would suffer from complications of COVID-19 and were frightened by the risk of contamination and the progress of situations that could lead to prolonged hospitalizations and invasive care measures, especially intubation.

She is already at a high risk of developing a major complication, of being intubated, having to stay in the emergency room. (I3)

I1	I2	I3	I4	I5	I6	I7	I8	I9	I10
12	4	7	10	6	14	7	9	13	11
I11	I12	I13	I14	I15	I16	I17	I18	I19	
10	9	11	2	9	12	15	11	14	

Chart 1 – Ages of children/adolescents with SCD whose mothers were interviewed. Feira de Santana, Bahia, Brazil, 2021
Source: Research data.

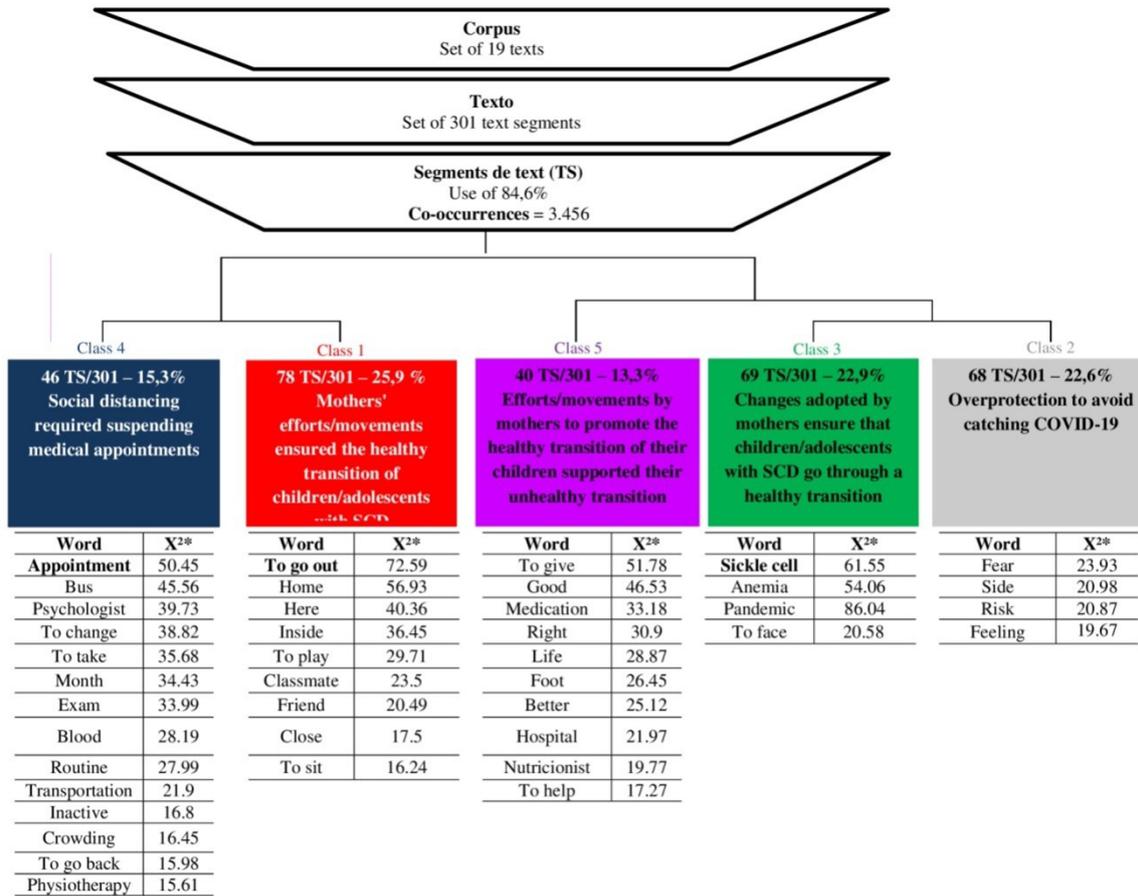


Figure 1 – Thematic structure of the research corpus according to Descending Hierarchical Classification
Source: Elaborated by the authors, 2021.

We know that he is more susceptible than other children, so we are afraid that he will get COVID and have serious complications, that's what we fear. (I13)

worried because I know it's a pandemic, it's a dangerous virus, which can be anywhere, so I always try to clean my daughter, her hands, and wear a mask (I8)

Changes adopted by mothers ensure that children/adolescents with SCD go through a healthy transition

Afraid of a probable contamination of the child and adolescent, the mothers intensified the use of recommended care measures such as hand washing, frequent showers when returning from public environments and mask-wearing, as shown below:

When my husband gets home from work, I tell him to take a shower right away, I tell him to wash his hands right away, and sometimes it's scary, because whether he likes it or not, he works with people. (I2)

I had to go out to work, but I always make a lot of recommendations, I try to be always attentive and I still feel

Other measures for the prevention of COVID-19 infection were adopted by the participants: staying at home, restriction on visitors and the limitation of contacts with other children and family members.

We don't crowd, we don't have parties, we stay at home isolated, just with the family at home, we don't receive visitors. (I10)

I also banned visitors. My family is aware, they are no longer coming to my house, and so we practically isolated ourselves. If we could, we'd put him in a bubble all this time. (I12)

Mothers of children/adolescents with SCD perceived greater vulnerability to the transmission of COVID-19 in public transportation due to crowding. Thus, fearing contamination, these mothers adopted strategies such as not using public

transportation, in order to avoid peak hours and crowds, and investing their money in Uber while traveling to health services, as highlighted in their statements:

We were very scared and she didn't go to physiotherapy either, because I'm afraid she'll get contaminated, I don't have my own car and I'm afraid to put her on these buses and the like, etc. (16)

I went with him to the appointment taking all the precautions, I didn't take the bus, I went by Uber, I came back by Uber and I did the exams. (116)

Given the difficulties faced with public transportation during the pandemic, these mothers asked their family members for help in getting around, as they reported:

And regarding transportation, in the morning my son takes us by car, before he goes to work he takes us to the hospital, and on the way back we take the bus. (11)

I always schedule a day when my husband is at home to take us somewhere, so we don't have to take the vans, I'm really afraid. (17)

Mothers' efforts/movements ensured the healthy transition of children/adolescents with SCD

The new care routines and practices to protect children's health and reduce the risk of contamination by COVID-19 led to a limitation of group games and family visits, as can be seen in the following statements

I prefer to leave her at home, and she complains because she wants to go to her cousins' house, or else to her grandmother's house. (15)

We spend more time indoors playing, I do everything for her to have fun, but I don't let her go out to play with her friends because I'm scared. (17)

The mothers reported that the incorporation of remote school activities changed the routine of children/adolescents with SCD. This factor also led to a sedentary lifestyle due to social isolation and lack of physical activities:

The children didn't go to school anymore, my daughter had to take classes online, do activities at home, and I realized that all this caused some damage. (18)

Go to school [...]. It was a little difficult, because she already had a routine, and this routine was completely modified because she became sedentary, having to stay indoors without doing anything, without doing any physical activity, without going out, without being able to play. (118)

Quitting a job due to concern about the contamination of children with SCD by the virus was mentioned by one of the mothers in the study, as follows:

At first, we were very scared, my husband had to leave work, I was working and left my job. (17)

One mother reported that the biggest challenge was guiding the child with SCD regarding strict protection measures in order to prevent contamination, such as wearing a mask and staying at home:

Sometimes he wanted to go out, he wanted to go somewhere, he wanted to go for a walk, and we had to get it into his head that he couldn't, that it was risky, that he was going to die. (116)

On the other hand, mothers of children/adolescents with SCD reported that their own routines were not significantly impacted by the pandemic, as they were already used to care practices similar to those recommended by health authorities for virus control, due to the fact that the children's immune system is compromised due to SCD and due to the constant risk of infections, as evidenced in the following speech:

She really likes to stay indoors, she likes to play with her dolls, she likes to scribble in her notebook, doing activities, watching television, playing games, so her routine has not changed at all during the pandemic. (13)

Social distancing required suspending medical appointments

In order to mitigate the transmission of the coronavirus, social distancing has been established as a mandatory health measure worldwide. Monitoring of health services and treatments performed by children/adolescents with SCD were discontinued and added to the families' fear of exposure to the new coronavirus. Discontinued physiotherapy sessions worsened the children's physical conditioning and impaired the prevention of new crises, as evidenced in the following statements:

She is always at home, she does some exercises at home with me and her sister. This is not solving the problem, I am not seeing a very positive result with the exercises she is doing at home [...]. I am really missing physical therapy in her life. (16)

She had several complications, because she was inactive for a long time and recently she resumed physiotherapy, because the referral service started working again. (118)

Despite the discontinuation of physiotherapy sessions, mothers of children and adolescents with SCD adopted a routine of daily stimuli and physical exercises, in order to try to keep them active during isolation and not compromise their health, such as their ability to stretch, respiratory capacity and the prevention of painful crises.

Efforts/movements by mothers to promote the healthy transition of their children supported their unhealthy transition

The lack of employment, school and support networks marked the trajectory of mothers of children/adolescents with SCD since the beginning of social distancing, since they were harmed by the lack of support. Thus, in the transition generated by the pandemic, mothers found themselves under stress due to the overload of full-time care and spending more time with the children:

For a mother, sometimes it is stressful to have to be like this, playing with the child all day. Sometimes this is stressful because the child asks for attention all the time. (12)

She just wanted to be with me the whole time. She called me all the time to play around. (19)

The level of stress increased in family environments due to the exercise of reconciling work with housework and activities with the children, enhancing the stressors present in mothers of children/adolescents with SCD associated to the overload of these activities and the long duration of the quarantine, in addition to uncertainties about the end of the pandemic.

■ DISCUSSION

This is the first study in the Brazilian context that examined the experiences of mothers of children/adolescents with SCD during the COVID-19 pandemic in the light of Afaf Meleis' Theory of Transitions. The data reflect the repercussions and

significant changes in daily lives of families for the incorporation of new measures to protect and prevent the spread of the virus in the midst of the care routine imposed by SCD.

According to socioeconomic data of the study participants, it can be affirmed that the mothers' reports emerged from a context in which children/adolescents with SCD were in a situation of social and programmatic vulnerability, due to the delay in the government response in providing/assuring the resumption of health services to monitor and control the disease and the lack of essential social resources for the physical protection of children and adolescents. Restrictive protective measures such as staying at home, fear of contamination, the impossibility of accessing some essential services for coping with SCD and the discontinuity of care impact the care routine of children/adolescents with SCD and their families, characterizing an unhealthy transition.

Given the scenario of social chaos, the uncertainties and the lack of information experienced during COVID-19, it can be said that the disease did not generate, but made explicit and sharpened the elements that constitute the social fabric in each affected territory, reducing its material and objective conditions for responding with preventive measures, medical and hospital care and social assistance⁽¹⁶⁾.

Unequal access to health services impacts the outcome of the disease, revealing the importance of control and prevention measures. This situation leads to a reflection on the inadequacy of public policies and the neglect of social vulnerability indicators in the investigated group⁽¹⁷⁾. Thus, the mothers experienced the insufficiency of their social role when they coped with the pandemic, mobilizing themselves by adopting their own strategies to prevent the spread of COVID-19, experiencing the phenomenon of transition.

The lack of public policies contributes to a transition process where the caregiver's role is insufficient, as mothers recognize their impossibility to support their children. Low socioeconomic status is an inhibitor of a healthy transition, as more vulnerable individuals are more likely to present psychological symptoms in the face of transitions⁽⁹⁾.

In the light of Meleis' theory, two transitions were identified: situational and health-illness. The situational transition refers to changes in the roles played by mothers of children/adolescents with SCD, in view of their need to assume new responsibilities and care due to the discontinuation of health services. This transition consists of events, expected or not, that trigger changes and lead people to face and adapt to the new situation that triggered such change⁽¹¹⁾.

The health-disease transition is a consequence of the onset of COVID-19, an emerging disease that changed the routine of children and adolescents with SCD (risk group)

and their families, in their attempt to deal with the virus to achieve a healthy transition.

As for the duration of transition, it is expected that it occurs over a period of time with an identifiable end point, ranging from the first signs of anticipation, perception or demonstration of change to a period of instability, confusion and distress⁽¹⁸⁾. However, the uncertainties and the pressing risk of contamination suggest that at the time the mothers reported their experiences, the situational transition caused by the pandemic was in a period of great instability, and it was not possible to identify markers of its end.

Thus, because the mothers feared the threat to the lives of children, the transition experienced mobilized these mothers to raise awareness about the fact that their children are at high risk of death. This awareness was favored by the accumulated experience and the learning acquired during the care of children and adolescents with SCD about the disease itself, in their search for health services, a context that also provides guidance on the new disease, its forms of transmission, prevention and control.

Hence the adoption of changes in the daily lives of children/adolescents with SCD and their families to face COVID-19 consisted of strategies that favored a healthy transition process.

A healthy transition is determined by the individual's response patterns to the transition process, which can be done through process and outcome indicators that allow identifying whether the person is predisposed to health and well-being or towards vulnerability and risks⁽⁹⁾. The factors that favored healthy transitions were support from family members to travel to health services and mothers' adherence to the new routine of daily stimuli and physical exercises to keep children active during isolation.

Social distancing was a fundamental safety measure at the beginning of the pandemic to prevent contamination by COVID-19, but it contributed to the development and/or worsening of anxiety and depression, which in turn may imply the adoption of a sedentary lifestyle that leads to chronic health conditions. Therefore, practicing breathing exercises (respiratory physiotherapy) during the vaso-occlusion process can prevent complications in SCD, such as acute chest syndrome and very severe respiratory complications, which makes the discontinuation of visits to physiotherapy and the progression of a sedentary lifestyle worrying during the pandemic in children/adolescents with SCD^(19,20).

The measures recommended by health authorities were incorporated by mothers into pandemic care routines. This change favored a healthy transition of children during the pandemic, but, in contrast, led mothers to an unhealthy transition, as they had to deliver part of the care of health

professionals whose services were discontinued, such as physical therapy.

Thus, the more mothers need to play the role of caregivers of their children, the more they neglect their self-care and become more vulnerable. The factors identified that favor unhealthy transitions were absence of remote care in essential follow-up services for children/adolescents, discontinuation of care for physiotherapy services and maternal overload for devoting more attention to children/adolescents with SCD during the course of the pandemic.

Participants in this study reported situations that characterize the transition process as of role insufficiency, since non-access to school reconfigured society, and families began to incorporate, in addition to work duties, the activities developed by students due to the need to maintain employment and income and confinement in reduced spaces. The closure of schools reduced face to face connections and everyday social interactions, which eventually resulted in considerable stress in this context of Covid-19 pandemic. Children and adolescents have become physically less active, which can be explained by the fact that they have spent more time in screen activities (smartphones, television and others), which are harmful to their full development^(21,22).

Concern is even greater with the main risk groups regarding complications caused by COVID-19, which is consistent with the statements of the participants of this study. The role of physical exercise for people in the risk group has three specific pillars: functional capacity, control of comorbidity and improvement of immunity. Before the pandemic, many mothers had established restrictive agreements regarding the exposure of children to cell phones and computers to make them more active. However, such agreements had to be renegotiated due to the fact that these devices are essential to maintain the emotional and social connections of their children with the extrafamily environment^(8,23).

Although mothers provide the best possible care for children/adolescents with SCD and are primarily responsible for care, providing guidance on covid-19 prevention measures for children/adolescents with SCD, this was also a challenge for most of them.

During the pandemic, in addition to performing their work activities, fathers and mothers of children face the overload of family care to their children, which tends to generate stress and is associated with less tolerance to deal with children's behavioral and emotional reactions⁽⁸⁾.

A higher level of stress among parents is associated with a higher level of irritability in children and may favor the increase in conflicts between parents and their children, generating a feedback cycle. Parents of children and adolescents overwhelmed by the pandemic life changes also

manage the daily lives of their children, minimizing the impact of the current circumstances on the mental health of children and adolescents^(7,8).

In addition, the relationship between parents and children tends to be affected in families where there has been quitting or loss of employment, due to concerns with financial restrictions or difficulties to maintain family support, such as food acquisition, personal hygiene items, and medications. In the pandemic scenario, families undergo situations of over-indebtedness, mostly because of unemployment, decreased family income, contamination and deaths of family members, as well as uncertainties regarding the future⁽²¹⁻²⁴⁾.

A limitation of this study is that listening was done only from the maternal perspective because of non-access to children and adolescents, as well as other family groups that might have added other elements of experience related to people with SCD during the pandemic. As contributions to research, the study points out, through the theoretical contribution of Nursing, strategies adopted by groups in vulnerability that enabled a healthy transition in the context of the pandemic and that can integrate the planning of care during situations of crises, epidemic outbreaks, natural disasters or other humanitarian crises, in order to minimize the worsening of the disease and maintain the biopsychic and social balance of all those involved.

■ FINAL CONSIDERATIONS

The present study attempted to analyze the transitions experienced by mothers of children/adolescents with SCD after the emergence of the COVID-19 pandemic, and concluded that the mothers' efforts/movements ensured a healthy transition of children/adolescents with SCD during the pandemic and at the same time collaborated for the unhealthy transition of these mothers. The results of this study reaffirm that nursing care should be expanded to support children and adolescents with SCD and their families towards a healthy transition in situations of crisis such as the one experienced in the pandemic.

The transitions described here show us that the discontinuation of services at all levels of health care triggered role conflicts and increased the vulnerability /-to unhealthy transitions, both for sick children and adolescents and for their respective families – and especially for mothers.

In the context of the pandemic, the intersection of challenges generated by the invisibility that surrounds SCD is very harmful not only for those who affected by the disease, but also for all those who are part of the family system. The strategies adopted by the groups to promote a healthy transition point to the strengthening of family ties,

interaction through social networks and remote interaction with health professionals.

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