

Existential analysis of mothers in the care of their children with Sickle Cell Disease

Análise existencial das mães no cuidado ao filho com Doença Falciforme
Análisis existencial de las madres en el cuidado al hijo con Enfermedad Falciforme

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ABSTRACT

Objectives: to unveil the experience of mothers of children who had a cerebrovascular accident due to sickle cell disease. **Methods:** qualitative, phenomenological research based on Martin Heidegger's philosophical framework. Ten mothers participated in the Association of People with Sickle Cell Disease of Minas Gerais. For the interpretative analysis of the reports, we performed the vague and medium understanding followed by hermeneutics. **Results:** the study revealed that, for the mother, the experience means remembering the diagnosis of the disease that had a significant impact. These women are in the center of care, and the consequences of stroke cause suffering. In this wandering, they seek to educate their children as close as possible to normal. **Final Considerations:** the study pointed out that we should look at these mothers seeking to see the multiple facets of their existence to the challenge of caring for the existential complexity of the human being.

Descriptors: Mothers; Stroke; Sickle Cell Anemia; Women's Health; Nursing Care.

RESUMO

Objetivos: desvelar o vivido de mães com filhos pós-acidente vascular encefálico pela doença falciforme. **Métodos:** pesquisa qualitativa, fenomenológica, embasada no referencial filosófico de Martin Heidegger. Participaram dez mães da Associação de Pessoas com Doença Falciforme de Minas Gerais. Para a análise interpretativa dos relatos, realizou-se a compreensão vaga e mediana seguida da hermenêutica. **Resultados:** desvelou-se que, para a mãe, o vivido significa lembrar o diagnóstico da doença que teve grande impacto. Os cuidados são centrados nessas mulheres, e as sequelas do acidente vascular encefálico são motivos de sofrimento. Nesse caminhar, buscam educar os filhos o mais próximo possível do normal. **Considerações Finais:** o estudo apontou que devemos olhar para essas mães buscando enxergar as múltiplas facetas do seu existir para o desafio de cuidar diante da complexidade existencial do ser humano.

Descritores: Mães; Acidente Vascular Encefálico; Anemia Falciforme; Saúde da Mulher; Cuidados de Enfermagem.

RESUMEN

Objetivos: desvelar lo vivido de madres con hijos tras accidente vascular encefálico por la enfermedad falciforme. **Métodos:** investigación cualitativa, fenomenológica, basada en el referencial filosófico de Martin Heidegger. Han participado diez madres de la Asociación de Personas con Enfermedad Falciforme de Minas Gerais. Para el análisis interpretativo de los relatos, se realizó la comprensión vaga y mediana seguida da hermenéutica. **Resultados:** se desveló que, para la madre, lo vivido significa recordar el diagnóstico de la enfermedad que tuvo gran impacto. Los cuidados han sido centrados en esas mujeres y las secuelas del accidente vascular encefálico han sido motivos de sufrimiento. En ese curso, buscan educar los hijos lo más cerca posible del normal. **Consideraciones Finales:** el estudio apuntó que debemos mirar para esas madres buscando percibir las múltiples facetas de su existir para el desafío de cuidar frente a la complejidad existencial del ser humano.

Descriptores: Madres; Accidente Vascular Encefálico; Anemia Falciforme; Salud de la Mujer; Cuidados de Enfermería.

INTRODUCTION

Sickle cell disease (SCD) is a genetic, autosomal recessive disorder that includes abnormal hemoglobin variants. It originates from a single nucleotide mutation in the sixth codon of the β -globin gene, leading to the formation of hemoglobin S (HbS), which polymerizes under lower oxygen tension, causing sickle-shaped red blood cells, which cause inflammatory processes, vascular occlusion and damage to the endothelium⁽¹⁾. It is a severe chronic disease characterized by hemolytic anemia, episodic vaso-occlusion, and progressive organ damage. Sickle cell anemia is the most common and most severe form of the disease and occurs due to the homozygous of the sickle cell gene⁽²⁾.

According to data from the National Program for Newborn Screening, for every 1,000 live children births in the country, one has SCD, and it is estimated 3,000 children a year with SCD and 180,000 with sickle cell trait. It is a non-communicable chronic disease of prevalence and clinical importance in the Brazilian public health scenario⁽³⁾. It is possible to characterize the pathology is a clinical variability among patients who, during their lifetime, learn to take care of themselves by interspersing periods of well-being and complications.

Cerebrovascular accident (CVA) is one of the most severe complications of SCD, accounting for 20% of patient mortality. It occurs due to a decrease or complete interruption of cerebral blood flow. It may present in the ischemic (CVAi) or hemorrhagic (CVAh) form. CVAi has a thrombotic cause, generated by interruption of blood perfusion in a part of the brain, which leads to brain dysfunction. In the CVAh, blood extravasation occurs in the cerebral parenchyma, caused by the rupture of a vessel, which is usually associated with blood pressure spikes or an already sick and sclerosed vasculature⁽⁴⁻⁵⁾.

Studies reveal that parents suffer daily challenges by managing their children's health problems alongside the care requirements imposed by chronic disease. Such challenges can generate a negative impact on their lives and cause emotional, behavioral, physical, and social shocks. In this scenario, mothers appear as the primary caregivers, and the increase in actions performed by them, to the detriment of child-directed care, may cause work overload due to the centralization of care in the figure of women, a fact that occurs commonly in our society. We realize that, culturally, women are responsible for the day-to-day chores, which, gathered and intensified, can cause stress, impacting everyday activities⁽⁶⁻⁷⁾.

A differentiated look at this mother who performs care, and needs to be cared for, should be given by the nurses in their practice. It is essential to raise feelings and perceptions. There is a need to address factors such as doubts, fears, insecurity, as they will directly influence their process of seeking and maintaining health. According to Watson⁽⁸⁾, when two people approach, in a caring gathering, their life stories and unique phenomenological fields cover an event, which creates an opportunity, a real occasion for the care. Nurses must join these mothers on their health, disease, and healing journey, willing to perform care meetings.

In the search to know about the phenomenon, following the perspective of being, we find in Martin Heidegger's phenomenology the possibility of understanding the daily life lived by

these mothers who are cast in the world, living in their facticity, presenting singular characteristics that make them unique.

OBJECTIVES

To unveil the experience of mothers of children who had a cerebrovascular accident due to sickle cell disease.

METHODS

Ethical aspects

Before the research, we obtained the authorization for its development from the Board of The *Faculdade de Enfermagem da Universidade Federal de Juiz de Fora* (Nursing School of the Federal University of Juiz de Fora- UFJF) and the president of the *Associação de Pessoas com Doença Falciforme* (Association of People with Sick Cell disease) of a municipality of the Zona da Mata Mineira. The present study was registered on the Brazil platform, *Sistema Nacional de Informação sobre Ética e Pesquisa envolvendo Seres Humanos* (SISNEP - National Information System on Ethics and Research involving Human Beings). After considering all the ethical aspects presented on Resolution 466/2012⁽⁹⁾ and Resolution 510/2016⁽¹⁰⁾, we were approved by the UFJF Ethics and Research Committee. We identified the participants as follows, to ensure anonymity: use of the letter I, followed by the cardinal number representing the order of the interview (ex: I1).

Study participants

The participants were ten mothers who had children affected by CVA due to SCD. Inclusion in the study was thus defined: women over 18 years old, mothers of a child aged 6 to 29 years old who suffered stroke due to SCD, regardless of color, religion, and sex, and who consented to participate in the research presenting conditions to articulate thought and speech, making themselves understood by the interviewer. The following were excluded from the study: mothers of children under 6 or over 29 years old who did not suffer a stroke due to SCD, mothers who could not articulate thought and speech, not being understood by the interviewer.

Type of study

Qualitative research that used the existential phenomenology of Martin Heidegger as a theoretical, philosophical, and methodological foundation.

Study scenario

The research was conducted from September 2017 to March 2018, in the Association of People with Sickle Disease in a city of the Zona da Mata Mineira, which is a legal entity under private law, which has the purpose of defending the rights and interests of people with sickle cell disease in all society. It presents itself as a philanthropic, cultural and social welfare organization, nonprofit, partisan, or religious.

Data collection and organization

Initially, we contacted the association's president, who referred us to the first mother who met our inclusion criteria. This mother nominated another participant, and so on. When there were no more appointments, we would return to the association's president, who would nominate a new mother. This technique is known as snowball or snowball sampling and has enabled us to obtain a non-probability convenience sampling.

We used a phenomenological interview to obtain the data, performed individually, in places agreed with the participants, and conducive to in-depth dialogue, safeguarding their anonymity. In the first part of this script, we collect information that allowed us to construct the participants' historiography (age, schooling, family income, city of residence, age, and gender of the child and other complications of the child except for CVA). In the second part, there were two instructions: "Tell me what your daily life is like with your son. Tell me what is the meaning of this daily life for you."

The interviews lasted an average of 50 minutes and turned into an intersubjectivity meeting, in which the principal researcher performed sensitive, attentive listening, and reduced assumptions⁽¹¹⁾. Throughout the dialogue and the empathy established, other questions arose that helped to understand the meanings of these mothers' experiences.

A methodological resource used for this research was the field diary, which allowed to record the historicity of each meeting and the uniqueness of each mother. This diary provided the researcher with the opportunity to make a note of the interviewee's modes of expression, gestures, emotions, silences, pauses in speech, glances, tears, and laughter, allowing meanings to emerge in these women, which would not be possible to be captured through spoken language, to legitimize the discourse. In the search to unveil the phenomenon, we seek to give voice to the entities valuing and seeking to understand their feelings, behavior, emotions, attitudes, and opinions, what is present in their life world⁽¹²⁾.

The participants permitted to record the dialogues, which transcribed by the leading researcher, maintaining the fidelity of the language of these women.

Data Analysis

Data analysis took place at two methodical moments following Heidegger. In the first stage, we performed a vague and medium understanding, in which interviews were read and reread in order to highlight what was prevalent in the speeches, aiming to capture the essential structures of the phenomenon. These speeches were grouped to build the Units of Meaning (UM), which are what women expressed from the questions directed to them, through which we seek to explain what the entity thinks and speaks about being, opening the horizon to unveil the facets of the possible investigated phenomena⁽¹²⁾.

Through the units of meaning, we were able to work out the guiding line so that we would move toward the second methodical stage, according to Heidegger, the interpretive or hermeneutic understanding. At this moment, having as theoretical, philosophical, and methodological base the phenomenology of Martin

Heidegger, we seek to clarify the meanings of this experience so that the question of being could come to the presence.

RESULTS

The participants were ten mothers aged between 25 and 48 years old. Nine of the interviewees reported having a family income between one and two minimum wages, and only one said to have an income of three to five wages. As for the city of residence, five live in the city where we conducted the survey and five in nearby municipalities. Regarding the level of education, five of these mothers had not completed elementary school, and four had completed elementary school, and one completed high school. The children's ages ranged from 10 to 24 years old, of which nine were male and one female. Six of these children were affected by comorbidities other than CVA: two by heart diseases, one by Moya-Moya, two by epilepsy, and one by fibroadenoma.

Gradually, as we interviewed the entities, immersed in their daily life, we were building the UM, in which common and different meanings of the mothers' experiences came to light in the face of the questions presented. Then these six following UM emerged:

UM 1 – The feelings experienced when the child's diagnosis was revealed — a mixture of ignorance and suffering;

UM 2 – The mother as the primary caregiver and the care overload;

UM 3 – Faith as a singular welcome in the face of suffering;

UM 4 – CVA – sadness, and difficulties in the acceptance process;

UM 5 – Family and friends support in coping and caring for the mother;

UM 6 – Mother's perspective on facing the child's comorbidity.

UM 1 – The feelings experienced when the child's diagnosis was revealed — a mixture of ignorance and suffering

The memory of the moment when the child was given the diagnosis of SCD brings to the fore feelings, and singular perceptions lived peculiarly by each woman. The impact of the diagnosis of the disease was difficult to understand by the lack of knowledge of pathology. The scare was present in these reports accompanied by the sadness represented by the "crying" that occurred at that time. Another report that emerged was the "shock" in the face of the new reality set for them at that time.

The impact of future treatment, which would be continuous and for the rest of their life, were the factors responsible for this feeling.

I didn't even know what it was like, so I took fright. (I1)

Because when I had [say the son's name], I did not know that I had a trace of sickle cell anemia and neither his father, then my life was all about him. (I2)

Geez, I cried, I cried. I was in the hospital. I remember it to this day. (I4)

So... At the time, I wasn't even so afraid much because I didn't know it, I didn't know, you know? And then, over time, I started to understand. (I5)

It was shocking [...] to do treatment for the rest of life. It was like this [...] very impacting. (I6)

At first, I even thought it was something else. I thought he had Down syndrome because until then, I didn't even know what sickle cell anemia was; after I was referred here [quotes the treatment site], they were explaining to me what it is, then I started calming down. But first, I got a fright at first, it's very difficult. (17)

I didn't even know there was such anemia [...] For me, to tell the truth, I wasn't afraid of anything because I didn't know what sickle cell anemia was, they said to me like this: "Oh, he has sickle cell disease." For me it was almost nothing, I had no idea it was going to be such a serious thing, because, for me, that's pretty serious. (19)

Sickle cell anemia, for me, is not a big deal anymore; it was, a while ago, it was, but today not anymore[...] That's because I didn't know what it was. (110)

UM 2 – The mother as the primary caregiver and the care overload

When facing the conjuncture of being a mother, these women present themselves as the primary caregivers of children who suffered CVA due to SCD, reporting the abandonment of their daily tasks to the task of caring, of living according to their children. These women became responsible for promoting and coordinating care, changing their dynamics of life so that this was possible. The dependence of children generates a high demand, which can cause overload and tiredness due to the responsibilities and routines imposed by this day by day.

Some people pick on; they are always out; some mothers go out. I do not, I do not go out anymore, I just take care of her [...] I live for her [...] We miss it, we feel bad because we have colleagues, a lot of people, but first of all, comes her [...] a heavy load that I say is like this: you need patience, there is the time for the medication, a heavy load in the sense that you need to have everything at the right time. (11)

And a fighting life, you have to fight, run. You have to do this, do that. It's exhausting. (12)

Because my life lives according to him [...], I live for him like, totally. [...] It is a hurry, get off work, rush, go to school and pick him up when he is feeling sick, it's very difficult. [...] Tired, I'm tired. [...] when he got sick, his dad left, so I feel tired because everything is me, I have to solve it all, and sometimes I feel exhausted. (13)

So taking care of him is a constant. Constant and all the time, right! [...] I think that's the real thing; it's taking care. [...]. (quotes own name) is on account of it. There is no, like (quotes own name) is the mother. [...] exhausting. (16)

It is a hurry. You have to split yourself. While you have your chores, you have your main attention, that is the sick child. (18)

It's too exhausting. No one helps me [...]. But I can tell you it's not easy. It is not! The fight is tough, even more so that it is me alone, not alone, alone and God [...] I can't even explain sometimes why it's tough, but it's tough. It is too exhausting [...] Sometimes I'm being medicated up close to him, so I don't leave him alone... not even like that, if I call someone and talk, no one will come. That's why I find it very exhausting, you know! Overwhelming. (19)

Oh, to tell the truth, I don't have a day for myself. My day is all day for them. It's a hurry there, and it's rush here, now I'm not even caring about cleaning up the house, cleaning the kitchen, stressing. [...] And time for myself, I don't have it, because I have to go to the doctor, I have to look for a doctor for me urgently, but there's no time. But we're hanging in there. (110)

UM 3 – Faith as a singular welcome in the face of suffering

Spirituality and faith are essential tools used by these mothers as strategies to cope with the new situations imposed in this daily life. The certainty and hope of a better future, already predetermined by God, who knows all things, provide comfort and a sense of confidence that what is to come will be better. Daily care coming from God for their lives gives them the feeling of relief, help, and strength to cope with all the difficulties that arise in this journey.

Gee, I am very pleased, thank God, nothing is missing. Nothing, nothing, nothing, thank God [...] The important thing is to pray, ask God to give us strength, and carry on. (11)

So I think I have a lot of faith in God, a lot of faith. I don't think. I'm sure the Divine Holy Spirit. He acts on me as a very wise woman. [...] all this comes from God because if it's not for God, we can't get anything. (12)

It is all in the hands of God; whatever happens, it is because God allowed it to happen, and that's it. (16)

I believe God gave him to me because He knows that I am capable of taking care. Besides him, I have another girl with hearing loss, so I think God chose me. Because God sent me two special children. (17)

Satisfied and, another word, blessed, for being willing and for God preparing me for this [...] Thank God, I feel very honored to have been able to walk along with it to get this far. [...] God only gives the burden, the cross, according to our potential to carry it, and if God gave me that cross, that is a sign that He knew that I would bear to carry it as far as He wants. (18)

Let's carry on with our lives as far as God thinks we can. [...] My God, why does it hurt so much, he starts screaming: "Mom, help me, mom, my God, help me." Then you do what you can there. Oh my God, what can I do more. There were days when I knelt on the floor right there and said: My God in heaven, I can't take it anymore, because this boy feels so much pain. [...] But it will get better, God willing. (19)

Now, thank God, there is nothing Our Lady Aparecida cannot help with. I'm taking them every year, everyone goes with me to Aparecida do Norte, so it has been six years since they were interned, thank God. (110)

UM 4 – the cerebrovascular accident – sadness and difficulties in the acceptance process

Sadness was one of the feelings that emerged from the new reality imposed due to CVA. The memory of having a child that was previously normal, in contrast to the new reality of having a more dependent person because of this affection, makes them

not accept the situation experienced in their daily lives. Here there is the report of not understanding and apparently not wanting to understand this newly imposed situation.

So... at first it was very sad. I wouldn't conform at all, geez, it was a shock. [...] you go out with a normal girl and come home with her like that, it was crazy, you know. It was something I never believed [...] there are times when we say it like this, my God, what is this, a beautiful girl, wonderful, very good, geez, everyone liked, likes her, even today, because now they like her even more because she's so strong, she's a warrior, she's a warrior. (I1)

Sometimes I fight with him, and after I regret it, I cry, I suffer because he is 12 years old, and I want to force him to act like a 12-year-old and I can't. (I3)

After he had these seven strokes, it got harder, you know. And for everything, I have to be with him. He can never be alone. [...] Oh, I suffer because I see him that way, and he wasn't that way, and now he depends a lot on me, and on his sisters as well. Not being able to do anything on his own, I suffer with him too. (I5)

UM 5 - Family and friends support in coping and caring for the mother

Family and friends appear as a support network in the face of the demands of daily care. Mothers report the importance of this support and the great relief they feel, knowing that they have it when the demand becomes intense.

The people of the community are all united. When somebody travels, and I have to bathe her, the other is already in the other's house saying: oh, when it is time will you help [says own name]. [...] That's how things are, everyone is together, thank God. Glad that everyone there helps because otherwise, it would be a little complicated. (I1)

Like in this case, there is [says the name of the partner] that helps me a lot, there is an appointment, he will go. (I3)

Dear God, I think, being honest, since [says the son's name] was born that I knew of his illness; my mother was the one who helped me because I couldn't do it myself. [...] It's my mother, really. My mother with my son is more mother than me; she and my stepfather help him a lot [...]. But, what makes it easier is the support of my mother, you know. (I4)

My daughters help me a lot, especially [says her daughter's name], who takes him to blood transfusion, to physical therapy. Depending on which doctor, she takes him to me, you know because I work. Gee, she helps me a lot. (I5)

Gee, the one that helps a lot is my husband, he has a health problem, and he is on sick leave, so that's what helps me, what helps me rest a little. (I6)

Oh no, here at home, everyone does a little bit. I do, my husband does, my other son does, my daughter-in-law is there, also helps, here at home each one does a little. [...] Then I like it, you know? But when I have to do things by myself, it's very tiring. (I10)

UM 6 - Mother's perspective on facing the child's comorbidity

We observed that some mothers raise their children as close to normal as possible when comparing them to people without the disease. There is a concern for the future and the adaptation in everyday life. These women yearn for their children to feel inserted in a social context and not to feel different from others. There is the wish, expressed in the speeches, that they could seek their independence and do not think of needing any help because they have the SCD.

We must have that rule. When she's throwing a tantrum, we have to call her attention, because we can't let her, because otherwise, it will be too much. We don't know tomorrow that only God knows. If she has some improvement, she will even hit us. (I1)

So far, he is 11, I never had the courage to go to INSS [Brazilian Social Security Institute] to request a benefit for him, I never had the courage, because I always imagined that he is a normal person to me, so I have never gone after it [...]. So, I spoke to my daughter [she is 24 years old]: "Don't talk to him [say son's name], don't talk to him, because he has to know that he is a normal person [...]" I rather not talk to him, so he knows he has to study, he has to grow up and his life is a normal life. Some people do like this: "Oh, poor thing." If the person is next to me, I answer: "Hey, my son doesn't have anything, my son is strong, healthy, he can do everything, he will grow up and go to work." (I2)

I raise him as if he were normal, you know [...] I know he needs care, but I don't go on saying to him, I let him live as if he were a normal child, because he already suffered a lot from it, for example, he even talks to me: "Oh, mom, why is it just me from the kids that have a problem? Only I have to go to the hospital?" "Got it? Then I started taking care of him as if he were a normal child. (I4)

I try to be normal with him, so to not be different, because he feels it, you know? [...] Normal, I stay at home normally with them. There is no difference, no. So I avoid even showing that there is a difference. Normal. (I5)

There was a day that it was raining, that rain pouring down, and he sees the other kids playing, and he said he wants to play just like them; I mean, I don't, why don't I? For fear of something happening, he could catch a cold, feel pain, but my desire is to let him play with his friends too. That is, we get sad. (I9)

DISCUSSION

The being-mother-of-a-child-with-sickle-cell-disease showed as being-there, immersed in the world of references, an entity that, in daily life, is launched, alternating between authenticity and inauthenticity in their living experience. The Dasein, being-there, behaves differently and does not show itself as other entities within the world, because it has its way of being⁽¹²⁾.

Having a child with SCD has a significant impact on the acting and thinking of these mothers. This being-there immersed in its existential facticity experiences the lack of knowledge at the moment of receiving the diagnosis that is given to the child, causing fright, shock, and sadness. This world that presents itself to them has a high impact and makes them reflect on the weight

that this care will represent in their living experience and on the treatment that will have to be performed for the rest of their lives, proving to be a complex reality.

For these mothers, remembering the meaning of this diagnosis means reflecting on the entity's totality on the horizon of the historical world itself, in search of the truth of being. For Heidegger, we need not forget the past to move on. Often, going backward is moving forward in the sense of going deeper, to the beginning. What we seek is the proximity of an origin that can help us move forward. A non-chronological temporality marks us, so what is left behind is always in the present so that we can project ourselves into the future⁽¹³⁻¹⁴⁾.

In their existence, the beings-mother reveals themselves from the idea of care as a being-in-the-world in an unchangeable contingency, in which they perceived the impact of the care process on their lives. It is a life of dedication to the children with rush and exhaustion, which leads them to forget their own being and abandon their daily tasks. Mothers also report missing their ordinary activities, but deny themselves in favor of their children. The world presents itself to them as tiring, tough, and fraught with hardships, with many tasks. The Dasein is launched into an existence beyond their control that contains things not chosen by them⁽¹⁴⁾.

Heidegger presents care (*Sorge*) as something that belongs to human existence itself, the being-there. In this experience, we care about ourselves and others in the time course of our existence. Healing, in an equally original way, determines the fundamental mode of these entities, in which they immerse themselves in the world of occupation. It is possible to see more original care in the concern of these mothers who worry about their own existence and their children's existence⁽¹⁴⁾.

In this experience, mothers reported the importance of spirituality as support for coping with adverse conditions that arise. A provider God who lets nothing lacking in their life gives them the readiness to overcome their problems. This Being, which has allowed the condition of the disease in their lives, is the same one they could not live without to overcome the obstacles that arise. God is existential and experiential, being present in the lives of these mothers.

Relief from pain, suffering, anxiety, and psychological stress is supported by spiritual and religious practices, which are one of the most common and ancient forms used by man to make sense of human existence. Faith, as a unique welcoming, has been a tool of great relevance in people's lives. The Dasein as a being-in-the-world is thrown in a being-into and a being-alongside religiosity and spirituality, expressed by faith in God⁽¹⁵⁻¹⁶⁾.

In this living, mothers refer to the sadness they felt and feel regarding the new condition of their children's dependence due to CVA. Here appears the condition of not understanding how this happened. The memory of a child who was considered "normal" and now needs more intense care, due to the new health condition imposed, generates suffering. These women are anguished when accompanying all the suffering and obstacles their children need to overcome. They share with them the suffering, disability, and restriction that may result from the disease.

Anguish is a way of being-in-the-world, for anguish is proper of the being. In this relationship that exists between mother and child, it is possible to understand the suffering of others.

Heidegger presents this understanding, not as a need to insert oneself into another's life by replacing or intruding on their life but intending to promote one's life out of concern⁽¹⁴⁾.

In this walk, the help of family and friends proved to be important in the lives of these mothers. The support provided by these other intramundane beings, in the web of relationships that they establish in daily life, is related to support in caring for the children, monitoring them, and providing transport to take them to the treatment. In carrying out these operating procedures, friends and family members come to be the mother-in-the-world for the concern about these women, immersed in a routine that they claim is exhausting. Their role is reflected in their affective relationship with this being-mother and can provide comfort, rest, sharing the joys and sorrows, emotional and structural support when they become necessary⁽¹⁷⁾.

In difficult times, mothers feel the presence of other entities, not only performing actions for them (characteristics of the occupation) but also seeing them as beings-of-potentialities. Dasein's world is a world shared with others. These "others" do not mean the other people, the other being-there besides Dasein itself; if so, we would subject the possibility of isolation of this being. By "others," we mean those of which ourselves do not differ, "among whom one also stands," in a similitude in being, occupied within circumspection as being-in-the-world. This world, to which the Dasein is thrust into a relationship of co-presence, comes to meet others in many different ways⁽¹⁴⁾.

In the reports, we see these mothers' efforts to educate their children as if they did not have the disease - paraphrasing their lines, "as if they were normal." There is a concern to create ways for them not to feel excluded and different from others and to seek conditions for a better future, for example, through study. It is also a way to avoid the suffering of the children experienced when they recognize themselves as different from others.

Constructing this reality means a redefinition of the parameters of normality for control over the disease and a return to the family routine that these women have often lovingly constituted. Not showing to the children that they are sick and that they have "limits" in some way due to the pathology is an important way of socialization in the different social contexts of this child in a search for acceptance and respect in daily life⁽¹⁸⁻¹⁹⁾.

While the future itself has the character of "anticipating" or "fore-running" (*Vorlaufen*), the improper is an "awaiting" (*Gewärtigen*). In the improper way, the Dasein expects the future to do something of it, while in its own way, it resolves itself and anticipates possibilities and does something of its own⁽²⁰⁾. The consciousness of finitude leads individuals to awaken to the possibility of the impossibility of existence, leading them to advance themselves, where Dasein opens up to themselves, "concerning its most extreme possibility," projecting themselves for a more meaningful and authentic potentiality for being⁽¹⁴⁾. Projecting oneself for a shared future with these children seeking normality in the living experience, which is already phatic, presents itself as a potentiality for being in the most appropriate way of these mothers' own existence.

Study Limitations

In line with the methodology applied in this study, we truly believe that the research results cannot be generalized to other

mothers since the phenomenon is unique and lived uniquely by each being-in-the-world. We know that openness to the issue of being provides us with the foundation for nursing care that seeks to assist, respecting the individual demands of each person, in an exercise of being-with-the-other in the world of care, which is something singular and peculiar of the nursing practice.

Contributions to nursing, health, or public policy fields

The present research was relevant so that the being-mother could be unveiled and shown as itself, clarifying the lived phenomenon, thus providing valuable knowledge to the planning of a care practice that approaches the other and is not only critical, reflective and scientific, but that dignifies itself through the broadened look at the beings cared for and at those who present themselves as caregivers.

We hoped that the results might propose, in daily nursing care, a look at this caregiving mother who needs to be seen and welcomed, as she usually becomes invisible before the care demands for not being sick. This study points to the need for dialogue and the professional approach to this woman, to sympathize with her pains, to be close to being able to reason in a way that allows us to raise their specificities of guidance and care, without generalizing, without setting standards but seeing her as a unique being. We hope this look will give professionals the chance to intervene in the quality of life we care for and make them feel regarded.

Given the findings of this study, we suggest that the intervention of any health professional does not reduce these mothers to an object that must respond rationally to events and external stimuli. The recommendation is that these professionals accept the existence of experiential realities in other non-physical and biological environments, providing the caregiver with the opportunity to the being-in-the-world of caring/healing, moving towards a human practice, welcoming and effective.

FINAL CONSIDERATIONS

Being-mother in the 21st-century context means much more than parenting, giving birth, and caring. The option of motherhood, by itself, already configures a choice for challenges that require daily overcoming. Being the mother of a child who has sickle cell disease and is also affected by a stroke has proved to be a fateful reality permeated by various obstacles that she must overcome at all times.

Through the research, we realized that the Dasein is always launched into an existence open to relationships, a reality that was not chosen by them but needed to be faced. Looking at these mothers also implies looking at the relationship they establish with their children and the developments that this relationship can generate in their physical, mental, and social well-being. It is up to us nurses and health professionals to have the ability to look, welcome, and provide conditions so that this mother does not perceive herself alone in the world of care.

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