



**FEELINGS OF WOMEN WITH SICKLE CELL ANEMIA WITH REGARD TO
REPRODUCTIVE EXPERIENCES**
**SENTIMENTOS DE MULHERES COM ANEMIA FALCIFORME EM RELAÇÃO ÀS EXPERIÊNCIAS
REPRODUTIVAS**
**SENTIMIENTOS DE MUJERES CON ANEMIA DE CÉLULAS FALCIFORMES CON RELACIÓN A LAS
EXPERIENCIAS REPRODUCTIVAS**

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ABSTRACT

Objective: to describe the feelings experienced by women with sickle cell anemia with regard to their reproductive experiences. **Method:** this is an exploratory, descriptive, study with a qualitative approach. The population consisted of 25 women with a confirmed sickle cell anemia diagnosis with previous reproductive experiences. A semi-structured interview was used for data collection. Data were approached through thematic Content Analysis. **Results:** through the analysis of interviews, the following categories emerged: fears and longings which fill the lives of women with sickle cell anemia during their reproductive experiences; feeling of family, financial, and conjugal insecurity; feeling of happiness, overcoming, and victory with regard to the gestational process; feeling of sadness, trauma, and frustration resulting from breastfeeding failure and complications inherent to sickle cell anemia. **Conclusion:** it was found out that women with sickle cell anemia showed a multiplicity of feelings with various influences – economic, social, and psychological – in their reproductive experiences. **Descriptors:** Sickle Cell Anemia; Women; Feelings; Nursing.

RESUMO

Objetivo: descrever os sentimentos vivenciados por mulheres com anemia falciforme em relação às suas experiências reprodutivas. **Método:** estudo exploratório, descritivo, com abordagem qualitativa. A população foi composta por 25 mulheres com diagnóstico confirmado de anemia falciforme com experiências reprodutivas anteriores. Foi utilizada entrevista semiestruturada para coleta de dados. Os dados foram abordados por meio da Análise de Conteúdo temática. **Resultados:** a partir da análise das entrevistas emergiram as seguintes categorias: medos e anseios que povoam a vida das mulheres com anemia falciforme durante suas experiências reprodutivas; sentimento de insegurança familiar, financeira e conjugal; sentimento de felicidade, superação e vitória em relação ao processo gestacional; sentimento de tristeza, trauma e frustração decorrente do insucesso da amamentação e das complicações inerentes à anemia falciforme. **Conclusão:** constatou-se que as mulheres com anemia falciforme manifestaram multiplicidade de sentimentos com diversas influências – econômica, social e psicológica – em suas experiências reprodutivas. **Descritores:** Anemia Falciforme; Mulheres; Sentimentos; Enfermagem.

RESUMEN

Objetivo: describir los sentimientos vividos por mujeres con anemia de células falciformes con relación a sus experiencias reproductivas. **Metodología:** esto es un estudio exploratorio, descriptivo, con abordaje cualitativo. La población fue compuesta por 25 mujeres con diagnóstico confirmado de anemia de células falciformes con experiencias reproductivas anteriores. Fue utilizada entrevista semi-estructurada para la recogida de datos. Los datos fueron abordados por medio del Análisis de Contenido temático. **Resultados:** las entrevistas emergieron las siguientes categorías: miedos y anhelos que pueblan la vida de las mujeres con anemia de células falciformes durante sus experiencias reproductivas; sentimiento de inseguridad familiar, financiera y conyugal; sentimiento de felicidad, superación y victoria con relación al proceso gestacional; sentimiento de tristeza, trauma y frustración resultante del fracaso de la lactancia materna y de las complicaciones inherentes a la anemia de células falciformes. **Conclusión:** las mujeres con anemia de células falciformes manifestaron una multiplicidad de sentimientos con diversas influencias – económica, social y psicológica – en sus experiencias reproductivas. **Descriptor:** Anemia De Células Falciformes; Mujeres; Sentimientos; Enfermería.

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INTRODUCTION

Sickle cell anemia is the most incident genetic disorder in Brazil and all around the world, and it's important during pregnancy due to the adverse effects on the mother and fetus.¹ Therefore, the pregnancy of a woman with sickle cell anemia is regarded as a high risk one – in which the life or health of the mother and/or fetus has more chances to be affected by complications.²

During pregnancy, a woman has experiences filled with intense feelings, in face of all physical and psychological changes which motherhood provides, which often lead to an exacerbation of sensitivity.³ In women with sickle cell anemia, pregnancy is a potentially severe situation, which can make her even more fragile and insecure.

Even with a high incidence of complications, these women live along with the positive feeling of getting pregnant, having children, and making herself happy through motherhood. Thus, during the gestational period, these women need a differentiated assistance, since, in these moments of joy and fulfillment, they also experience the risk of death and the fear that their child is born with the disease.⁴

Besides the changes and feelings usual to every pregnant woman, one identifies an increase of emotional and social problems for a pregnant woman with sickle cell anemia and her family, and also the presence of tension due to the fact that they have a chronic disease which causes a high risk of gestational complications. Aware of the risk that pregnancy poses, the desire to be a mother often goes beyond the disease's dimension and the option of having children must be ensured by the family and a good quality prenatal care.

Studies carried out with women with a chronic disease confirm the difficulties presented for emotional adjustments required by the new role and the emergence of feelings such as censure, guilt, and fear, with regard to themselves and the child's health, are usual in high risk pregnancies.^{5,6}

From this perspective, the relevance of the proposed theme and the fact that it's still poorly explored in Brazilian studies justify this research. One believes that the results of this paper can give a greater visibility to the problems faced by women with sickle cell anemia during the reproductive period and constitute a source of information for health professionals, especially nursing professionals.

The research question emerged from these considerations: "What are the feelings experienced by women with sickle cell anemia with regard to their reproductive experiences?". The aim was describing the feelings of women with sickle cell anemia through their reproductive experiences.

METHOD

Exploratory, descriptive, study with a qualitative approach, which is part of the research project "Reproductive experiences of women with sickle cell anemia", connected to the Group for Studies on Women's Health (GEM) of the School of Nursing of Universidade Federal da Bahia (EE/UFBA).

The subjects of this study were 25 women, selected according to the following inclusion criteria: confirmed diagnosis of sickle cell anemia; enrolled in the outpatient service of Hospital Universitario Professor Edgar Santos (HUPES) and/or connected to Associacao Baiana de Pessoas com Doença Falciforme (ABADFAL); age group from 18 to 49 years; previous reproductive experience; and signing of the Free and Informed Consent Term. The option for the age group between 18 and 49 years is justified by the fact that these women are within the reproductive period and they aren't minors.

The instrument for data collection had questions aimed at characterizing the sociodemographic and reproductive profile of women and questions trying to describe the feelings experienced with regard to their reproductive experiences. Data collection occurred from August to November 2011, through semi-structured interviews held at home.

Data analysis was performed using Content Analysis, in its thematic modality.⁷

For this research, the feelings experienced concern manifestations of sensitivity with positive and negative impacts; they refer to what women with sickle cell anemia thought, felt, realized, imagined, and underwent with regard to an experience of conceiving, giving birth, aborting, and going through the puerperal period. Thus, feeling includes various concepts, or various characterizations, or various ways to present oneself, since sometimes it indicates something good and pleasurable, whereas it also indicates something negative.

This study was approved by the Research Ethics Committee of EE/UFBA, and it met all ethical principles of Resolution 196/96, from the National Health Council (Protocol 12/2010; CAAE 0087.0.053.000-07).

RESULTS AND DISCUSSION

The analysis of demographic data shows that most of the 25 participants are within the age group from 30 to 40 years (52%), with a mean age of 36 years; 80% of them live in the city of Salvador and 20% in the countryside of the state of Bahia. Regarding race/color, one identifies that all participants are black; 56% declared themselves as being black colored and 44% brown colored.

Regarding marital status, the percentage of women living with a partner, married, or in a stable relationship, (14 women – 52%) is higher than the number of single women (8 women – 32%). Concerning education, no participant has higher education, however, 11 women (44%) reported having completed high school. Regarding the distribution of women according to family income, one identifies that more than half of them, 52%, have a monthly income of 1 minimum wage.

All women in the study had already got pregnant, and most of them went through the gestational process only once (11 women – 44%). The number of pregnancies doesn't correspond to the number of children, since some of them had complications, such as spontaneous abortion and stillbirth. Thus, not every woman who got pregnant has children alive.

Regarding maternal and fetal complications one identifies that most of these women (72%) presented complications during the gestational period, such as spontaneous abortion, premature birth, worsening of anemic condition requiring blood transfusion, painful crises, urinary tract infection, hypertensive disorder specific to pregnancy, stillbirth, low birth weight newborn infant, and jaundice.

The qualitative analysis of interviews allowed the identification of feelings expressed by women with sickle cell anemia with regard to their reproductive experiences through categorized speeches, which are presented below.

♦ Discourses of health professionals trigger fear and insecurity in women with regard to the possibility of getting pregnant

One identifies that interdictions, impediments, and doubts contained in the speeches of health professionals about the reproductive process trigger fear and insecurity in women with sickle cell anemia with regard to the possibility of getting pregnant.

I didn't avoid having a child. The gynecologist said I wasn't very fertile, so I thought I couldn't have a child. The gynecologist said that the patient with sickle cell anemia couldn't get pregnant and, sometimes, need to undergo a treatment. (I 18)

When I started knowing my husband better, I always told him that the doctor said I couldn't have a child because of sickle cell anemia. She said it wasn't possible to use anything, because it led to thrombi in the legs and, as I had a problem with ulcer, it wasn't good. (I 08)

Speeches made apparent the conflicts between the information from health professionals about the impossibility of getting pregnant and the life experiences of women with sickle cell anemia, since there's a widespread belief among health professionals that rarely women with sickle cell anemia are able to breed. Some of them were informed by health professionals that they couldn't get pregnant.

The women said they didn't use any contraceptive method because of beliefs echoed in the speeches of professionals. They reported sex with no worry that unprotected sex can result in an unwanted pregnancy, believing that the consequences of this act don't lead to a pregnancy or sexually transmitted infections (STIs).

The effective control of the conception led the society to an indisputable advance, as it facilitated the emancipation of women and their participation in the labor market, besides allowing families, through the reproductive planning, the adequacy of the number of children to their economic conditions. It also brought changes in mentality and customs, such as liberality in the sexual practice, something which translated itself, paradoxically, not into a higher birth control, but rather into an increase in the number of unwanted pregnancies or abortions.

One observes that, at no time, these women were asked whether they wanted to be mothers or not. They underwent the guidance by professionals about beliefs of infertility, something which favored a set of negative experiences with regard to pregnancy, since many of them weren't planned.

Therefore, the discourse of a health professional is presented in a power relationship and women had some resistance responses. Contrary to the myth of passivity, all women in the study got pregnant and, despite the negative experiences, it was

possible to identify it as an achievement towards reproductive rights.⁸ Besides, a study analyzing the meaning of motherhood for women with a heart disease and diabetes identified that, even with a medical contraindication, these women got pregnant.⁵

While the desire to be a mother can be interpreted as a possibility of resistance to the discourses of health professionals, it's much more feasible that in these cases a role model woman is played, whose main role is motherhood. The desire and possibility of having children are pervaded by conflicts for these women, since they live along with a chronic disease and the constructions and images which were formed throughout their socialization process.

The choice of contraceptive method depends on a joint analysis between the health professional and the woman, taking into account her particularities. Contraception through the quarterly use of intramuscular medroxyprogesterone acetate has been used by women with sickle cell anemia, a method which is reported as safe.²

♦ Fears and longings fill the lives of pregnant women with sickle cell anemia

The fact that some women have gotten pregnant by satisfying the desire of motherhood leads them to have feelings of guilt and "mistake", because it can result in a sick child who didn't ask to be born. Such conflicting feelings are found in most pregnant women, but it occurs more sharply in the actual presence of risk caused by a chronic disease.

I felt guilty for getting pregnant. Guilt by knowing I got pregnant and that I had high chances of having a child with the disease. At the time of delivery I was very scared indeed, very scared, I thought I was going to die at that moment of delivery. (I 05)

Guilt is related to the sensation of being able to cause any harm to the child and it emerges from the time when they believe to have failed or violated an order. This feeling undermines in a significant way the psychological balance, making it even more difficult to cope with the situation of pregnancy and birth.⁹ Thus, the woman blames herself because reality has created inner tensions she is unable to bear and the only way out, therefore, is blaming herself.

One finds out that the pregnancy of these women was also marked by a feeling of worry and fear of having a child with malformation or the disease. A study on feelings and perceptions of women in the gravidic-puerperal cycle who survived a severe

maternal morbidity confirms the findings of this study in the sense that in a risk pregnancy women experience a difficult period, in which their difficulties for emotional adaptation are intensified, emerging, due to it, the actual fear and the longing of having a child with some abnormality.¹⁰

I was just afraid that he was born with my same problem, that's my feeling, fear of giving birth to a child equal or worse than me. (I 18)

I was desperate because I couldn't give birth in any maternity hospital, I could deliver only in a high-risk maternity hospital. (I 12)

Pregnant women with sickle cell anemia experience fear in all its elements: fear of the unknown, unpredictability, and risk. This feeling was found in the speeches of most women when they reported the end of pregnancy, close to the time of delivery, as fear of their own death. The lack of reference on the high-risk maternity hospital intensifies fear of delivery and it denounces the lack of integral care during the gravidic-puerperal cycle.

One can identify in the speeches content a great expectation of having a child with sickle cell anemia on the part of women. Lack of knowledge with regard to the possible complications that they and their children are exposed to leads to fear and worry about the possibility of getting a child with sickle cell anemia.

In this sense, the probability of a pregnant woman with sickle cell anemia having a child with the disease will depend on the paternal diagnosis. Among women in the study, none had a partner with sickle cell anemia and they don't know whether their partner is a carrier of the sickle cell trait.

Fear is the prevalent feeling in pregnancy and, in a high-risk pregnancy, it's real, meaning a feeling of having no control over the situation and over what can happen to the mother and her son. According to the literature, there're seven crucial types of fear: fear of future dangers; fear as a feeling of uncertainty with regard to the results; fear as worry; ideological fear, expressed as fear of God, for instance; finally, existential fear, fear of death (one own's death or another person's death).¹¹ It's possible that when it comes to a pregnant woman with sickle cell anemia, all these fears described above are present.

♦ Family, financial, and conjugal insecurity

In this study, factors other than those caused by major changes of pregnancy,

influenced the emotional status of women with sickle cell anemia. Speeches where the reason for not remembering the gestational experience as positive was related to lack of family, financial, and conjugal support were identified.

One also notices that pregnancy brings up feelings of apprehension, because they're going through a moment of conjugal crisis, generating insecurity with regard to providing the child about to come with means. Some women report loneliness due to lack of family support.

I was very apprehensive, because I wasn't living well with my husband. (I 02)

I was pregnant and kept thinking that I had to work to support and care for my child. (I 04)

It was difficult for me. My family didn't support me. The child's father didn't care, I went to the hospital alone, often, and I sat there alone, without any help, so it wasn't a very good experience, indeed. (I 08)

It's important to take into account the pregnant woman's personal history, the existential context of this pregnancy (whether inside or outside of a marital relationship), the evolution features (if it's a risk pregnancy posing danger both to the mother and fetus), the socioeconomic context (the possibility of having a minimum amount of money), finally, the clinical context, since the interaction between these factors can directly influence the mental health of a pregnant woman.¹¹

Socioeconomic factors also influence the acceptance of pregnancy. In a society where, especially in urban areas, a woman usually work out of home and she's also responsible for the household budget, the fact of having a child entails significant consequences.¹¹ Thus, it was observed in this study that actual deprivations, whether affective or economic, increase tension and intensify feelings which make women remember pregnancy as a negative experience.

The lack of social and family support for people with a chronic disease can worsen emotional disorders and create problems to cope with situations. This social support is crucial for the well-being of these pregnant women with sickle cell anemia, and it can, in most cases, ease the existing tension.⁴

♦ Happiness, overcoming, and victory with regard to the gestational process

Women with sickle cell anemia in this study felt relieved, happy, and victorious because they were able to successfully go through the whole gestational period. These women expressed that the memories of this process

have brought them an enjoyable reminder and a pleasant experience.

My pregnancy was wonderful, smooth. At the time of delivery, it was also smooth and when the baby was born I was alive, that was a joy, it was very good. (I 05)

A good feeling, because I've been through all this. My daughter is fine and I will grow her. But now the feeling refers to relief, happiness. Of going through it all and being fine. A feeling of victory. (I 11)

Painful and suffering sensations can mark the memory of many women with sickle cell anemia. One finds out, in this study, that it's possible that new emotions emerge and surprise these women when they realize to be able to successfully go through this time, being able to conceive a new being. Feelings related to overcoming limits and capabilities come along with motherhood for every woman and they strongly influence the perception of the child's birth.

The choice of these women with sickle cell anemia to have children represents a victory for them, it brings a sensation of overcoming obstacles, such as the disease, death, and risk.¹² One verifies that the satisfaction which motherhood gives these women often outweighs any unpleasant feeling which they might have felt during pregnancy, bringing satisfaction and often mitigating the expectation and anxiety due to the unknown.

♦ Sadness and trauma resulting from spontaneous abortion and stillbirth

Among women who had more than one episode of spontaneous abortion and stillbirth, the feeling of sadness, frustration, and trauma were also found.

A lot of sadness. I lost the love of being a mother, I don't want to be a mother at all, after these losses I'm very afraid. (I 19)

It was frustrating, sad, a shock, going into the delivery room and seeing that your child wasn't born alive, that he won't leave the hospital with you. Afterwards, I was home with my family and there was also the process of giving everything, having to undo everything, I had already assembled everything. (I 09)

Fetal loss is a traumatic and frustrating event, especially for women who repeatedly miscarry, and it's possible to occur feelings of grief and frustration along with every new failure.

The definition of repeated abortion commonly accepted refers to three or more consecutive spontaneous abortion, although, in practice, a less stringent criterion is already adopted, two or more abortions. In about 50 to 60% of habitual abortion cases one

finds out one or more comorbid conditions which can be related to repeated abortion, including sickle cell anemia.^{13,14}

The sensation of failure due to unsuccessful pregnancy, in face of information on stillbirth, is a big shock for these women. Holding so many plans, dreams, and desires with regard to motherhood, these women are frustrated giving birth to a dead child, so, they go through a deep emotional sadness feeling. Thus, feelings of grief at the time of maternity hospital discharge are usual.

After receiving the news that the child wasn't born alive, these women go into shock and mourning comes soon. After leaving the maternity hospital, when arriving home, they need to get rid of everything they had prepared for the baby's arrival and, depend on the trauma generated, along with this process of getting rid of things, many women also get rid of the dream of motherhood.

♦ **Regret due to pregnancy complications and sequelae**

The feelings, as presented, aren't always positive. It was found out in this study that there's a feeling of regret. It was identified in a woman who had hip necrosis as a pregnancy complication.

When I discovered that it was a sequel of pregnancy, my son was already five years old. It was just at that time that I realized I should never have a child. Perhaps, if I hadn't had a child, I wouldn't be affected, you know? It was a kind of regret, indeed. (I 07)

In case of sickle cell anemia, a chronic disease, it becomes a must that a pregnant woman knows the risks resulting from a pregnancy, thus contributing to her own adaptation. A research carried out with pregnant women with diabetes mellitus in order to identify the knowledge on this chronic disease also found out that the problems surrounding the disease goes beyond aspects pointed out by respondents, revealing the importance of health education practices through an interdisciplinary approach, aiming to prevent possible complications, contributing to reach their best adaptation level.¹⁵

♦ **Frustrations resulting from breastfeeding failure**

Another feeling found was that of frustration due to being unable to breastfed her child or due to breastfeeding failure, highlighting the symbolism of the mother's ideal connected to breastfeeding.

No, I've never breastfed my child, indeed. It's a dream of mine, I'd like to breastfeed

my children, you know, but... There was no milk. I've never had. I've never produced it, never. (I 14)

She [the child] cried a lot, a lot... She nursed all night long and she was never satisfied. She always wanted to nurse, nurse, and, then, the nipple looked exactly like raw meat. (I 16)

Feelings of frustration were also found in women who failed to breastfeed their children. Frustration occurs when the woman is unable to fulfill a desire which was cultivated throughout her life. Failure to establish breastfeeding leads to this woman to have a feeling of sadness, along with a loss which is often unnoticed by the professionals who assist her, increasing the risk of postpartum depression.¹⁶

The set of results obtained and designed by the categories presented may be translated into feelings of fear, anxiety, and anguish which contradict the feeling of happiness in generating a new life in the complex daily life of having sickle cell anemia and being a woman.

FINAL REMARKS

The social reality presented by women in this study corroborates the results already found, such as the unfavorable economic situation of people living with sickle cell anemia and multiple complications presented during the gravidic period, thus representing a group of high social risk, since it presents a higher probability of maternal and perinatal morbimortality.

Given the aim of this study, one is able to know that the feelings experienced by women were permeated by the feeling of fear. One also identifies that women recognize the risks that pregnancy pose to their health, but they want to have children, although most of them haven't planned the pregnancy.

The pregnancy experience reported by this group of women showed to deserve attention, taking into account the possibility of providing this portion of population with a better biopsychosocial adjustment. As these women expressed, the desire for motherhood would be complete with the actual breastfeeding act. They claimed that the fact of being unable to breastfeed causes them frustrations, interrupted desires, and broken dreams.

It was noticed a high expectation of women with regard to the future of their lives and their children, during pregnancy and after birth, i.e. feelings of family, conjugal, and financial insecurity. They showed to be

worried, apprehensive, afraid of their own death, afraid of what is unexpected and of losing their child, or afraid that she/he were born with the disease. However, they expressed feelings of happiness, joy, and victory at the end of the gravidic period.

Sickle cell anemia has been the object of studies aimed at evaluating the prevalence rates, as well as clinical and genetic aspects. However, the literature is poor in terms of women's sexual and reproductive health. There's a need to find strategies to help them and their families in the process of coping and acceptance, showing a concern with the non-biological aspects which affect the pregnancy of women living with sickle cell anemia, as one of the ways to improve the quality of health care provided for these women.

As considerations for the nursing care to women with sickle cell anemia during their reproductive experiences, one emphasizes that the nurse, when performing the follow-up of low-risk pregnant women, in the basic health care network, must be aware of the results of laboratory tests, particularly hemoglobin electrophoresis, since a positive result for the sickle cell disease trait will reorganize the flow of this pregnant woman to more complex health care systems. Specific guidance should be given both at the basic level and at the follow-up of high-risk pregnancies, in order to prevent complications and prepare women to live along with this problem in a better manner.

By recognizing the magnitude of issues permeating the discussions on the specificities of health care for people with sickle cell anemia, caring for women with sickle cell anemia is a challenging role for nursing. The nurse and his team need to focus on these women as a whole: their pains, thoughts, anxieties, fears, among other factors, under a holistic perspective, understanding that the care process shouldn't be restricted to the identification of clinical signs and symptoms of the disease, it needs to address the deeper and subjective changes which shake the "being" of these women.

There's a need to know in a deeper manner the feelings experienced by these women during the gestational period, so that the interventions can contribute to overcome the obstacles posed by the gravidic risk, using an assistance aimed at a better quality of life, adaptation, and integration into the new role that she assumes by becoming a mother.

One hopes that this study can contribute to qualify nursing care, especially with regard to recognizing the diversity and amplitude of

needs of women with sickle cell anemia, ensuring them quality of information and care both to physical and emotional aspects, aiming to reach integral and not generalized care, health promotion, and prevention of problems to the maternal and child group.

Investigation on emotional repercussions during the gestational period is a promising and still poorly explored field. New researches addressing this pregnancy context should be carried out and made public, since few published papers with such an approach were found. One points out as one of this study's limitations the fact that women had already gone through the experience of pregnancy.

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