



Online Brazilian Journal of Nursing

E-ISSN: 1676-4285

objn@enf.uff.br

Universidade Federal Fluminense

Brasil

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Online Brazilian Journal of Nursing, vol. 12, núm. 4, 2013, pp. 834-843

Universidade Federal Fluminense

Rio de Janeiro, Brasil

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## Perception of women suffering from sickle cell anemia regarding pregnancy: an exploratory study

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### ABSTRACT

**Aim:** To analyze the perception of women suffering from sickle cell anemia regarding pregnancy. **Method:** This is a qualitative, descriptive and exploratory study, involving 25 women suffering from sickle cell anemia who lived in Bahia. Data were obtained through open interviews and analyzed by the Collective Subject Discourse. **Results:** Three central ideas emerged from the discourses: fear and anxiety marked the pregnancy of women suffering from sickle cell anemia; dilemmas permeated the decision to abort, and; the desire to be a mother was frustrated by miscarriage. **Discussion:** Due to the lack of equipment and lack of social support for exercising motherhood, women experience sadness, depression and think of interrupting the pregnancy. **Conclusion:** The choice to have children, although risky, should be ensured by public policy with an integral assistance to women suffering from sickle cell anemia, involving the totality of their reproductive trajectory.

**Descriptors:** Women; Anemia, Sickle Cell; Reproductive Health; Nursing Care; Obstetrical Nursing.

## INTRODUCTION

For women suffering from sickle cell anemia (SCA), pregnancy is a potentially serious condition that can leave them even more fragile and insecure. Even with a high incidence of complications during pregnancy, they live with the positive feeling of getting pregnant, having children and the achievement brought about by motherhood. During childbirth and the puerperium they require a differentiated assistance because in those moments of joy and fulfillment, they experience the risk of death and the fear that their child may suffer from SCA at birth<sup>(1)</sup>.

Pregnancy can aggravate SCA, with the increase in frequency and severity of painful crises and infections. The maternal-fetal risks include: an increase in vaso-occlusive crises in the pre- and postpartum, urinary tract infections, pulmonary complications, anemia, preeclampsia, and even death<sup>(2)</sup>. In fetal complications we can observe preterm delivery, intrauterine growth restriction due to placental vascular occlusion, fetal distress during labor and delivery, as well as the elevation of the rate of perinatal mortality<sup>(3)</sup>.

The most severe complications occur in women with hemoglobin SS (88%). Other social factors may contribute to the complications of pregnancy in women with SCA, such as problems of malnutrition and parasitic infestations, which can be dangerous to pregnant women and fetuses<sup>(3-4)</sup>.

Because of complications during pregnancy, SCA is considered high risk because the mother and/or fetus are more likely to have impaired health and their lives may be at risk to a greater extent than other women. Failure to perform prenatal checks, alone, can be considered a risk factor for any pregnancy.

Although women suffering from SCA are subject to risks during pregnancy, that does

not prevent them from desiring pregnancy. On the other hand, health services and health professionals are poorly prepared to care for these women, especially during pregnancy, which can contribute to increase the insecurity and fear they experience in this life stage.

The nursing staff who are in contact with women who suffer from chronic illnesses in their daily lives may intervene from the perspective of the appreciation of feelings and of physical, psychological and social conflicts. They should also play the role of facilitators of self knowledge strategies for women in the process of devising mechanisms for accepting their limitations<sup>(5)</sup>.

Prenatal care specialized for high-risk patients should be initiated as early as possible, and systematic monitoring should be offered, preferably by trained teams to reduce complications and properly treat them, thus reducing maternal and perinatal mortality.

According to the recommendations of the Ministry of Health, women with SCA should undergo prenatal visits with an interval of two weeks until the 26th week, and after that, consultations should be weekly.<sup>(6)</sup> It is important that they are met by a multidisciplinary team in order to ensure that all aspects of the pregnancy are covered<sup>(6)</sup>.

The interest for this study arose from the authors' approach to women suffering from SCA, both in care as in activities in research involving this subject. In this sense, this study started from the following question: How do women suffering from sickle cell anemia perceive pregnancy? And to answer it, we decided to analyze the perception of women suffering from sickle cell anemia regarding pregnancy.

With this study we aim to contribute to provide visibility regarding the reproductive experiences of these women and elicit the reflection of health professionals about the care provided to this group.

## METHOD

This was an exploratory, qualitative and descriptive study that investigated 25 women who met the following inclusion criteria: having been diagnosed with sickle cell anemia; being registered in the outpatient department of the University Hospital Professor Edgar Santos (HUPES) and/or being linked to the Association of People with Sickle Cell Disease from Bahia (ABADFAL); being an adult between 18 to 49 years of age; and, having reproductive experience.

This study was approved by the Ethics Committee in Research (EEUFBA) through Protocol no. 12/2010; CAAE. 0087.0.053.000-07, and met the recommendations of Resolution no. 196/96 of the National Health Council.

Empirical data were collected through open interviews when women were urged to respond to the following request: Tell us about your experience with pregnancy and sickle cell anemia. The location of interviews was previously negotiated with each participant so they occurred at the clinic and at home, in the period from August to September 2010.

For organization, tabulation and analysis of data, we opted for the Collective Subject Discourse (CSD), which is a qualitative way of representing the thoughts of the community. This is done by aggregating discursive contents of similar meaning, issued by different people in a single speech-synthesis, in response to open questions in an interview<sup>(7)</sup>.

## RESULTS

The 25 women participating in this study were mostly concentrated in the age group from 30 to 40 years (52%), with a average age of 36 years; 80% were residents of the capital and 20% were from the countryside of the State of

Bahia, Brazil. All of them described themselves as black women: 56% of them stated they were black and 44% had mixed skin color. Most were married or in stable relationships (n=14, 52%) and eight of them (32%) were single. More than half of them, 52% had a monthly income of only a minimum wage, and 11 women (44%) said they had completed high school.

Among the study participants, 14 women (56%) said they had been pregnant more than once.

With regard to maternal and fetal complications, we found that most of these women (72%) had complications during pregnancy, such as miscarriage, premature birth, aggravation of the anemic status requiring hemotransfusion, pain crises, urinary tract infections, hypertensive disease in pregnancy, occurrence of stillbirth, and newborns with low birth weight and/or jaundice.

From the qualitative analysis, three central ideas of CSD were identified: fear and anxiety were characteristics of pregnancy of women suffering from sickle cell anemia; dilemmas permeated the abortion decision, and; the desire of being a mother was frustrated by miscarriage.

In the first central idea of CSD, "**Fear and anxiety are characteristics of pregnancy of women suffering from sickle cell anemia**", we identified the feelings and conflicts experienced by women who were fearing the complications of SCA during pregnancy, which left them uneasy over the whole period preceding delivery.

From the discourse of these women it was evident that pregnancy was marked by complications for them, culminating in frequent hospitalizations for the management of symptoms and complications of the disease.

"My pregnancy was complicated. I felt so much pain, too much pain indeed. I took medication during the whole pregnancy [...]. I had much trouble; I

was hospitalized; was in great pain; I had a urinary tract infection, fever and pain. In the third pregnancy I also had many complications; I was hospitalized and I also had a urinary tract infection and I had blood transfusions twice.” (CSD 1)

Likewise, orthopedic complications, pain crises, urinary tract infections and hemotransfusion have been reported during pregnancy.

The women revealed that, during pregnancy, they nurtured their concern about the lack of vacancies in a reference maternity hospital for high-risk pregnancy that offered structured services and trained professionals to assist them, as they understood that SCA adds risks to this vital process.

In this CSD it is also clear that the concern of pregnant women regarding the lack of vacancies in referral maternity hospitals was intensified when they received an alleged “hospital discharge” of prenatal care and were guided by the professionals themselves to seek for services with expert assistance.

“I was worried because the doctor told me that if I arrived at the hospital in pain to give birth and there were no vacancies, I’d have to go out looking for vacancies in other hospitals. This made me very worried and desperate because I couldn’t have my baby in just any maternity hospital. I could only have it in a high-risk maternity hospital. I had many crises during pregnancy. I had many complications, such as swelling. Because of low hemoglobin, I needed to take a blood transfusion in HEMOBA before delivery. As for the feelings I guess I was not even thinking about them. It was very painful, too much

pain. I hardly could wait for it all to end. Well, joy, I felt no joy, no, but I also felt no sorrow [...] It was in the hands of God because He could do everything. I dunno, I was pregnant, I kept thinking I had to work to support my baby. I thought I had to look after him. I dunno, I thought about dying.” (CSD 2)

In their discourses, the women suffering from SCA, emphasized that they were afraid of having sick children; they felt scared of dying during childbirth or that the baby would not survive. These thoughts were reported often, being affected by crying, anger and hopelessness.

The low economic status of women and the chronic disease process were combined in various difficulties in their lives; therefore, when they got pregnant they felt unable to care for the child.

From the discourses above, it can be observed that the pregnancy of women suffering from SCA, although highly desired, is a process affected by worries, fears and sadness in the face of negative expectations, material shortages and lack of support from health services and the family itself.

In the second CSD idea, “**Dilemmas permeate the abortion decision**”, women pointed out the conflicts, doubts, hesitation and impasses that they experienced when they were pregnant and the thoughts they had of resorting to abortion in order to preserve their own lives, because they feared that pregnancy may result in death or having a child with the disease.

“When I got pregnant my family didn’t know. I hid it from them because I was too afraid of what they would do to me when they found out. I lived with my uncle; I have no mother and no father. I didn’t do any treatment, I didn’t do prenatal, I did nothing, and then I took something and took another. I took some tea. I took

some of a few tea leaves that are sold out there. People say that it helps menstruation descend if it is delayed. I also took that medicine called Regulator Xavier. I used many teas, many things. But I really aborted through the use of Cytotec. Then I asked God to forgive me, because I know it is a sin, but I'll do anything not to have this baby. I had never taken it, I was afraid. Even if I die, I don't want it, I don't want it. It is very difficult to have a child alone, without a father, without support, nothing.

You have to handle everything. Everything depends on you. I started getting scared of having a sick child; so much that, when I see a scene of a child with any problem, I don't look at it. Even in my pregnancy I never looked. I said: 'Oh my God, forgive me, I know it is a sin, but help me losing this child.' Then I said I was not going to have this baby. God forgive me, because I know it's a sin, but I don't want it. I have already suffered a lot. I thought about it, but I was afraid. I felt guilty. At the time I worked here in Salvador. My companion at first was wonderful; after I got pregnant it was terrible. I had no support. I had an abortion and that was it." (DSC 3)

Thinking about abortion promotes a sense of guilt in these women, because they understand that this measure as a "sin" against God, but at the same time they suffer with the expectation of giving birth to a sick, malformed and dependent child within an unfavorable family context since they don't feel that they are supported or they do not have the necessary resources to take on motherhood alone. Thus, they seek various ways to terminate a pregnancy, ranging from the use of herbs to different medications.

The decision to abort is a solitary measure for these women, because they do not receive any support from their partners and family. They cannot talk about that decision with friends or health professionals because it is a criminal action.

The third idea originated in CSD, "**The desire to be a parent is frustrated by miscarriage**", shows that women who chose to continue the pregnancy, due to their desire to be a mother, experienced the disappointment of not having the maternity achieved due the spontaneous interruption of pregnancy as a result of complications of the disease. This moment is referred to as a significant loss in the lives of these women, marked with suffering and sadness, which often develops into a depressive state.

"Oh, it's very sad, really sad. Today, I lost the pleasure of being a mother. I don't fight for this anymore. No way. I'm afraid. I had the desire of being a mother. It was a dream. But today I don't have this dream anymore, because I suffered the loss. I already loved my baby. It was a girl and I loved her so much. Look, you've already heard of those people who have difficulty having children, who have sickle cell anemia. Just because they know they can't have a baby, they want to have it. I was sad because I didn't have success in my pregnancy. I couldn't even see the face of my child. And the doctor didn't show me. The doctors came only to tell me that my child had died, but they did not show me the child. No. Oh, it's really sad, it's horrible. I even won a doll (laughs). Then when I saw a little baby in the hands of other people, I would start willing to have that child. I didn't care, I wanted it, that's what I wanted.

My companion also wanted this child very much. I went to the juvenile court to adopt one. If I saw someone with a bunch of kids I wanted to grab it. I almost went crazy, because after that my husband ended up with another woman and she became pregnant. I was mad with depression. Only then I let go other people's children. I play with the children of my neighbors. For me, my child had to survive, I only thought about that. I had great faith in God that my child would survive." (CSD 4)

From this discourse, it is observed that women have their dreams of being a mother frustrated due to intense suffering brought about by miscarriage. Successive losses and interventions on their health, which is already weakened by abortion, motivate them to give up any aspiration of having children, and encourages them to reshape their plans, establishing effective bonds with children who may be their nephews, children of their neighbors, or else they may sublimate their desire by caring for dolls and pets.

Moreover, a progressive change in self-image and loss of self-esteem can occur because of several visible bodily changes that make women with SCA to feel less attractive. The pregnancy and the arrival of a child means that they can match other women considered "normal". When women suffering from SCA are not fulfilled in motherhood, they live with the fear of losing their partners to other women who can become pregnant and give birth without much risk.

## DISCUSSION

SCA is manifested during the phase of women's lives when they are expected to be

more productive, moreover, the fact that this is a disease of greatest prevalence in African descendants who live on the margins of society in many aspects of their lives, is an aggravating factor. People suffering from SCA are stigmatized, that is, they are considered, in most cases, unable to respond to socially valued moral prerogatives<sup>(1,8)</sup>.

The participants in this study said they feared reporting the pregnancy to their families. This finding was also found in other studies involving pregnant women with SCA in southeastern Brazil<sup>(1)</sup>. In the same study, the authors emphasized that the joy of being pregnant is mostly expressed by women in their first pregnancy and that their fears are experienced more by women who are in subsequent pregnancies.

The ability for the women to cope with the disease and its complications is often due to the support received from the social environment, especially their families. This support modifies the effect of stressors, providing better conditions for women to deal with the adversities of the disease and thus provide them with better life quality.

Women's psychological resources and family structure interact and may contribute to their adaptation to the disease. Family support and the skills of each family member are important sources of information and they influence the way a person deals with suffering<sup>(1)</sup>.

The choice to have children is a victory for them. This option gives them a sense of overcoming obstacles such as illness, death and risk<sup>(8-9)</sup>. However, this expectation is transformed over time due to suffering from past experiences. Thus, women suffering from SCA who get pregnant for the first time increase their expectations about motherhood and decide to get pregnant guided by the emotion, while women with experiences of pregnancy, hospitalization, and/or abortion, are more rational and have fewer expectations of being a mother again<sup>(10)</sup>.

In a study performed with 42 pregnant women suffering from SCA, 25 (49.0%) of these women had at least one painful crisis during the prenatal period, which led to hospitalization for treatment. Blood transfusions during the prenatal period were performed in 14 (27.5%) of women and is indicated for the improvement of pain crisis or improvement of blood indices when the pregnant woman have severe anemia<sup>(3)</sup>.

The participants affirmed that, with pregnancy, they experienced more pain crises and recurrent infections, including urinary tract infections. Studies have shown that maternal complications are frequent, especially the infectious ones, bringing considerable morbidity to pregnancy. When evaluating occurrences of pregnancy in women suffering from SCA, urinary tract infection was the most frequent problem, accounting for a quarter of cases, while pneumonia was presented as the second most common infection, with 23.5% of cases<sup>(3,11)</sup>.

A study in Southeastern Brazil with 42 high-risk pregnancies identified that in the hospitalization before delivery, the occurrence of urinary tract infection, pneumonia, pulmonary hypertension and fetal growth restriction were significantly more frequent in the group of women suffering from SCA. This same study revealed that the need for blood transfusions during delivery or postpartum was significantly higher among those suffering from SCA compared to those with sickle cell trait<sup>(3)</sup>.

The fear of death and the death of their child is justified by the history of women who experience these complications. The women become aware of this fear from the reports of other women affected by the disease or from those who have had similar experiences in the family. Studies highlight that pregnancy in women suffering from SCA is associated with birth complications and high incidence of fetal

distress due to the inherent growth restriction that occurs in these pregnancies<sup>(3,9)</sup>.

In this study, women reported their experiences with repeated hospitalizations. Each time these could be life-threatening for the mother and child. As SCA is a neglected chronic disease, the diagnosis can be delayed, and this often means numerous attendances at emergency services and frequent hospitalizations, which are moments of imbalance and difficulties, are common in the everyday life of these women<sup>(8)</sup>. Thus, based on their own experience during the illness, women suffering from SCA construct ideas about what they might experience in their gestation.

Access to quality prenatal care is often hampered for women suffering from SCA, either by physical and economic limitations to access services, or by the discrimination suffered because of their race, gender and low social class, in which these women find themselves.

The difficulty of access to hospitals is one of the main factors responsible for maternal deaths<sup>(12)</sup> This loss is related to the hospital "pilgrimage", that is, the fact that pregnant women in labor often have to resort to more than one institution before being admitted, thereby contributing to the delay in the assistance to be provided. The absence of vacancies, which is the phenomenon of hospital pilgrimage, was a source of distress for the women studied.

With so many negative experiences in the process of chronification of the disease, the poor economic conditions of these women, the high degree of dependence that they have on their families, their fears of death and the fear of becoming pregnant with a child with the disease make them think about abortion, which is identified by means of CSD in this study.

The dilemmas experienced by women suffering from SCA before an unwanted pregnancy are similar to other groups of women and, after



deciding to abort, this abortion is a completely unassisted and solitary experience. Therefore, at the moment of the decision, they do not find support from their partner or family members. They become aware of the status of these women, generally, after they have already used the abortive substance or when they are in the hospital for emergency care<sup>(9)</sup>.

Women who abort make a judgment of themselves based on existing social consensus; they think of how they will be judged for their acts by the health team that provides care and even by the family when they return to their homes. Their concern lies in the fact that they have purposefully caused an abortion in a society for which this attitude is considered a crime<sup>(13-14)</sup>.

In this sense, women suffering from SCA suffer in advance for any possible sanction and judgment they might face if the people next to them identify that they sought such a measure. The decision to abort is always assigned, individually, as a women's responsibility. However, it is noteworthy that the social and family contexts, in which the women in the abortion process are inserted, are neither analyzed in the perspective of health care, nor the circumstances that led to the decision to terminate pregnancy.

The context of women suffering from SCA presents scarce material resources, since the majority are poor and have no formal job or individual income, most of them are dependent on the family for their support and their marital relationships are weakened by sickness and constant hospitalizations. All of this influences their decision to abort, and that decision is burdened by feelings of guilt, fear, self-loathing and self-punishment<sup>(13)</sup>.

Moreover, the reports show that women use various abortion methods combined, in their eagerness to solve the problem, thus exposing themselves to risks and complications. According to their report, the orientations for the use

of abortion methods and the realization of illegal abortions are performed by lay people, such as vendors of medicinal herbs, girlfriends and/or pharmacy attendants.

Abortion performed in unsafe and risky conditions is often accompanied by severe complications such as uterine perforation, infection and hemorrhage<sup>(9)</sup>, which are among the major causes of maternal death; it is an important factor of discrimination against women in health services, which hinders their search for these services<sup>(15)</sup>.

In the abortion process, women become desperate. They suffer from the abandonment of their companion and are judged by family members and health professionals. The social judgment starts in the family environment, and abortion comes from the censorship that women imagine they will receive from the family when it becomes aware of their pregnancy, because this was not the result of a stable relationship, or a balanced phase for the family. Thus, the decision to abort is a lonely decision<sup>(14)</sup>.

Abortion represents a high risk to the physical and mental health of women and it has a higher incidence in women who are young, of African descent and have a low educational level. Among these women are those suffering from SCA, who reside in the poorest regions of the country<sup>(16)</sup>.

Social factors, such as the cultural and economic conditions of the families, influence the women's motherhood projects. The facilities or difficulties to carry out such projects vary from one class to another, and depend on the situation and the quality of the health services available, the presence of the family and its support and the solidarity networks around these women. The material conditions of existence do not determine the choice for motherhood, but they interfere with the possibilities for their realization<sup>(8,9)</sup>.

However, the desire to have children is expressed in terms of claims regarding sexual and reproductive rights, as well as the new demands in the sphere of public policy, including health, requiring further consideration by the various individuals involved. The current value assigned to the family is the basic model of the modern conjugal family whose strength is expressed in the changes in family relations and sexual identities. Many of these women report a desire to realize the dream of their companions – paternity. One has to also consider the desire for children as the desire to constitute a biological family, which emphasizes the strength of the marriage bond and gender differences<sup>(17)</sup>.

Women suffering from SCA are at higher risk for maternal morbidity and fetal death. Proper care of the mother and neonate, from the beginning of pregnancy to postpartum, is essential for the care of these women. Because women suffering from SCA represent a very specific group, not only due to organ dysfunction secondary to the underlying pathology, but also due to the frustration of not exercising their reproductive and sexual rights frequently. Thus, many of these women develop severe mental health problems, such as depression and suicidal ideas during crises<sup>(1,3)</sup>.

## CONCLUSION

This study examined the perceptions about pregnancy in women suffering from sickle cell anemia and the results indicated that this moment is lived with great expectation and fear in these women, which are already weakened by the disease process.

Pregnancy adds necessities to handle all aspects of health and avoid risks to the mothers and their children.

When we become aware of the complications of SCA, we realize that pregnancy is marked by suffering, apprehension and guilt when these women fail to achieve success, or when they do not find social support for motherhood. Among the difficulties faced by these women there is an emphasis on the abortion decision, which arises from the discourses as an alternative is often thought by them to spare their health, to avoid a child who is affected by the disease, or due to difficulties in caring for a new baby with all the limitations brought by SCA.

For the fact that nurses are the professionals who mostly interact with these women in the care context, it is essential to include the theme that surrounds pregnant women suffering from SCA in their vocational training, so that these professionals get to understand the problems experienced by these women and adopt measures for receiving them, offering guidance regarding safe contraception, and quality prenatal care.

In the general context, these women have been receiving assistance for prenatal services, directed for women without chronic diseases, delivered by professionals who are less qualified to recognize the complex dynamics of chronic diseases.

This study points out to the need for greater investment by public policies, in the supply of skilled and specialized care services for women suffering from SCA within a multidisciplinary approach so that these women may exercise their sexual and reproductive rights without jeopardizing their health.

The choice to have children, despite being risky, should be provided by means of a comprehensive care program to women suffering from SCA that involves the entirety of their reproductive trajectory.

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**Received:** 28/02/2013

**Revised:** 24/11/2013

**Approved:** 01/12/2013