

REPERCUSSIONS OF FALCIFORM ANEMIA ON WOMEN'S SEXUALITY

REPERCUSSÕES DA ANEMIA FALCIFORME SOBRE A SEXUALIDADE DE MULHERES

REPERCUSIONES DE LA ANEMIA FALCIFORME EN LA SEXUALIDAD FEMENINA

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How to cite this article: Gomes AS, Ferreira SL, Moreira NS, Araujo LS. Repercussions of falciform anemia on women's sexuality. Rev baiana enferm. 33:e26945.

Objective: to identify the repercussions of sickle cell anemia in the sexuality of women. **Method:** This is a qualitative, exploratory study involving 25 women with sickle cell disease, members of an Association of People with Sickle Cell Disease, enrolled in an outpatient clinic of a public hospital in Salvador, Bahia, Brazil. The semi-structured interview and the technique of content analysis were used. **Results:** the following categories were identified: Body image compromised, as pain and fatigue alter the sexuality of women with Sickle Cell Anemia; and support from partners or their lack of it strengthens or weakens women with Sickle Cell Anemia. **Conclusion:** the manifestations of sickle cell anemia, such as pain and tiredness, are factors that negatively affect the sexuality of these women, provoking feelings of incapacity, frustration, causing them to fear not only facing new relationships, but also abandoning their partners. A support network, made up of family members or partners that values these women, strengthens them.

Descriptors: Sexuality. Sickle Cell Anemia. Women's Health. Body Image. Chronic Disease.

Objetivo: identificar as repercussões da anemia falciforme na sexualidade das mulheres. Método: trata-se de pesquisa qualitativa, exploratória, realizada com 25 mulheres com doença falciforme, integrantes de uma Associação de Pessoas com Doença Falciforme, cadastradas em ambulatório de um hospital público de Salvador, Bahia, Brasil. Utilizou-se a entrevista semiestruturada e a técnica de análise de conteúdo. Resultados: identificaram-se as categorias temáticas: Imagem corporal comprometida, a dor e o cansaço alteram a sexualidade de mulheres com Anemia Falciforme; Apoio dos companheiros ou a sua falta fortalecem ou fragilizam as mulheres com Anemia Falciforme. Conclusão: as manifestações da anemia falciforme, como dor e cansaço, são fatores que afetam negativamente a sexualidade dessas mulheres, por provocar sentimentos de incapacidade, de frustração, fazendo com que tenham receio não apenas de enfrentar novos relacionamentos, mas também do abandono pelos companheiros. Uma rede de apoio, formada por familiares ou pelos companheiros, que valorize essas mulheres, as fortalece.

Descritores: Sexualidade. Anemia Falciforme. Saúde da Mulher. Imagem Corporal. Doença Crônica.

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Objetivo: identificar las repercusiones de la anemia falciforme en la sexualidad de las mujeres. Método: se trata de una investigación cualitativa, exploratoria, realizada con 25 mujeres con enfermedad falciforme, integrantes de una Asociación de Personas con Enfermedad Falciforme, registradas en el ambulatorio de un hospital público de Salvador, Bahía, Brasil. Se utilizaron la entrevista semiestructurada y la técnica de análisis de contenido. Resultados: se identificaron las categorías temáticas: Imagen corporal perjudicada, el dolor y el cansancio alteran la sexualidad de las mujeres con Anemia Falciforme; Apoyo de los compañeros o su falta fortalecen o fragilizan a las mujeres con Anemia Falciforme. Conclusión: las manifestaciones de la anemia falciforme, como dolor y cansancio, son factores que afectan negativamente la sexualidad de esas mujeres, por provocar sentimientos de incapacidad, de frustración, lo que hace que ellas sientan temor no solo de tener nuevos relacionamientos, sino también de ser abandonadas por sus compañeros. Una red de apoyo, formada por familiares o por los compañeros, que valora a esas mujeres, las fortalece.

Descriptor: Sexualidad. Anemia Falciforme. Salud de la Mujer. Imagen Corporal. Enfermedad Crónica.

Introduction

Female sexuality can be affected by several reasons, such as symptoms of chronic diseases, use of medicines and/or daily worries. In addition to biological and psychological factors, sexuality can also be affected by the socio-cultural environment linked to individual aspects, usually introjected into the life experience and were influenced by culture. Another factor that can interfere is prejudice⁽¹⁾.

Women whose body is altered by pathology, malformation or accident may present a feeling of insecurity regarding body image. The uncertainty about acceptance provokes behaviors of fear of rejection that can favor the social isolation of these women. Social isolation reveals itself in different situations of everyday life, from wearing clothes, reducing affective contact or even restricting encounters with people from their social life⁽²⁾. Thus, being affected by a chronic disease, such as sickle-cell anemia (SSA), has many implications in women's lives, since their social life may be impaired in marital relationships, interpersonal relationships, the way they exercise their sexuality, and their well-being, in addition to modifying their self-image. All these factors directly interfere with the quality of life.

SSA, the most prevalent chronic and hereditary disease in the world, results from a change in the molecule of hemoglobin (Hb), where the abnormal Hb S is produced instead of the normal Hb A. In Brazil, 3,500 children with

SSA are born every year, with a predominance of Afro-descendants⁽³⁾. Data from the State Neonatal Screening Program show that, in the state of Bahia, the incidence of Sickle Cell Anemia is 1:650 among live births⁽⁴⁾. Feira de Santana, a municipality in the semi-arid region, presents a total of 4 cases per 10,000 inhabitants⁽⁵⁾.

SSA causes delay in sexual maturation. Early on, girls feel the impact of the disease on menarche and sexual characteristics, such as sexual desire, that appear late. As a consequence, retardation occurs in sex life, when compared to girls of the same age. The socialization of these young people can be quite differentiated, accentuating the inequalities of gender, race and class⁽⁶⁾.

The way women deal with SSA body changes is closely related to the way they view their bodies and their sexuality. That is, culturally, gender differentials imply how these people live their experiences. During adolescence, for example, there are a number of implications of SSA for girls, such as jaundice, the onset of first leg ulcers, and hormonal changes that result in delayed sexual maturation. Together, these body changes negatively influence self-image⁽⁷⁾.

This study is justified by the high incidence of SSA in the afro-descendant population, with emphasis in the city of Salvador, Bahia. This disease is considered a public health problem, linked to the socioeconomic factors affecting this population group, especially women⁽⁶⁾. Therefore, this study hopes to bring contributions

to broaden the visibility of the theme and provide the reflection of health professionals regarding the organization of the system and the services that offer assistance to women with SSA.

In the light of the above, the need to study the repercussions of SSA on women's sexuality is identified, since they need support to deal with negative experiences, based on prejudice and lack of understanding, in most cases from the partner, along with the lack of acceptance of the body itself.

The relevance of this study is in the recognition of the implications of SSA in the sexuality and social life of women, since it is extremely important for nursing to identify such aggravating factors and to provide a singular assistance to these women, for only knowledge allows qualified assistance.

Thus, it is believed that this study may contribute to increase the knowledge of health professionals related to the repercussions of sickle cell anemia on women's sexuality, as well as to improve and strengthen health care by the professionals responsible for the care of these women, in order to minimize the impacts on sexuality caused by this chronic disease.

The research proposes to answer the guiding question: What are the repercussions of sickle cell anemia in the sexuality of women? The objective is to identify the repercussions of sickle cell anemia in women's sexuality.

Method

This is a qualitative, exploratory study that integrates the project "Reproductive Experiences of Women with Sickle Cell Anemia", authored by the first author of the present study. In this study, there was the participation of 25 women who met the following inclusion criteria: have a confirmed diagnosis of sickle cell disease; be registered in the outpatient service of Professor Edgar Santos University Hospital (HUPES) and/or linked to the Association of Persons with Sickle Cell Disease of Bahia (ABADFAL); and to be an adult between 18 and 49 years of age. Women who reported some discomfort at the time of the

interview were excluded in order to avoid bias in the survey. A total of 25 participants were defined, using a theoretical saturation criterion.

Empirical material was obtained through an open interview, when women were encouraged to respond to the request: Talk about your sexuality and about having sickle cell anemia. The interview site was negotiated individually with the participants at an earlier time, so that they took place in the outpatient clinic and at home, from August to September 2010. A voice recorder was used so that the interviews were later transcribed. At the end of each recording, participants could withdraw or add information. The average duration of interviews was 20 minutes.

The study was approved by the Research Ethics Committee of the Nursing School of the Federal University of Bahia, CAAE no. 0087.0.053.000-07 and Opinion no. 12/2010. The participants of the study knew the objectives, justification and methodology and, if they agreed to continue, they signed the Informed Consent Term (TCLE, acronym in Portuguese). This study offered no physical risk to the participants, nor did it cause embarrassment, when reporting the facts of their lives. To reduce these risks, the testimonies were collected in a private setting and guaranteed anonymity. There was no need to refer the interviewees to the Health Service, since they did not present intercurrent due to the reports during the interview.

The data were submitted to the thematic content analysis of Bardin⁽⁸⁾, identifying different sense nuclei organized around three chronological poles: pre-analysis; exploitation of the material; and treatment of results, inference and interpretation.

Results

Twenty-five women with a confirmed diagnosis of sickle cell anemia provided by the SS hemoglobinopathy (HbSS), ranging in age from 20 to 50 years, participated in this study. Of these, 15 (60%) declared themselves black and 10 (40%), brown. The time of discovery of the

diagnosis of the disease among the participants varied between 3 and 39 years.

In terms of schooling, 11 respondents (44%) reported complete secondary education, followed by four (16%) with pre-school level, three (12%) with incomplete elementary education, three (12%) with elementary school education, and four (16%) with incomplete high school.

Regarding income, 13 (52%) reported being equal to one minimum wage, six (24%) had 1-2 minimum wages, four (16%) had income lower than one minimum wage, two (8%) declared having no income. As far as the profession was concerned, nine (36%) said they were home, seven (28%) had another profession, seven (28%) were retired and two (8%) received Social Security benefits.

In relation to the marital situation, eight (32%) reported being in a stable union, eight (32%) were single, six (24%) were married, two (8%) were widows and one (4%) was separated. Among those who were in a stable and married condition, seven (50%) reported full support from their partners, four (29%) reported not having support or perceived lack of interest on the disease by the companion, and three (21%) did not know how to report.

Among the 25 participants, 20 (80%) had children. Of these, 15 (60%) reported that the children had the SSA trait, two (8%) reported that their children had sickle cell anemia, and three (12%) participants were not able to report whether their children had the trait or SSA, since they were not able to perform a hemoglobin electrophoresis test to obtain the diagnosis. Of the 25 interviewees, 18 (72%) had partners. Of these, 11 (61%) did not know whether the partner had the trait or the disease, one had a partner with the trait of the disease and six did not have the trait.

The report of women with a confirmed diagnosis of sickle cell anemia made it possible to interpret the speech and identify the thematic categories: Impaired body image: pain and fatigue alter the sexuality of women with SSA; and the support of the companions or the lack of it strengthens or weakens women with SSA.

Impaired body image: pain and tiredness alter the sexuality of women with sickle cell anemia

In this category, it was possible to identify that the alteration in the body image causes a series of corporal and emotional manifestations that affect the sexuality and negatively repercussions in the daily life of the women.

[...] self-esteem interferes like this: People with sickle cell anemia have a characteristic of their own. Sometimes they think they're too thin. I have ulcer problem myself. My ulcer has healed, but the scar remains. I had already undergone gallbladder surgery, so there's the scar. I've already had grafting done. They took a tissue from my thigh and the scar remained. This interferes with our self-esteem; we feel ugly and down [...] (E.11).

It messes with sexuality, messes a lot, mainly because I have been disabled because of sickle cell anemia [...] (E.6).

The speeches reflect the distress felt by the women in the face of the bodily repercussions that sickle cell anemia causes. The emaciated aspect, leg ulcers difficult to heal, changes in gait due to ulcers, and other typical signs of the disease are experienced by these women, who tend to live with it and become accustomed to the intrinsic stigmas of sickle cell anemia.

Because SSA interferes with self-esteem, women do not feel attractive and think they are unfit to engage with the opposite sex. The feeling of impotence and incapacity are observed in the following reports:

As a woman, I sometimes feel unable to charm a person. But then, I realize I am able to do it. I am a determined woman; I like to dress me up. I'm very vain [...] but inside, I have a lot of prejudice, because of my problem [...] in relation to meeting someone, and be seeing my bandage or coming to my house and I being dressed in shorts [...] (E.17).

I see myself as a woman, but as an impotent woman. Powerless, yes, because I'm incapable of doing some kind of exercises, you know? I can't do everything. I avoid doing many things that the doctor says not to do: you can't exert yourself; you can't do that, you can't. So you feel incapable. (E.18).

The feeling of impotence reported in the discourses of women with SSA causes self-exclusion, believing that there is no possibility of initiating or maintaining a marital relationship.

The speeches allowed the identification of discourses and reports of pain crises associated

with fatigue, which led to the lack of sexual libido of women with SSA.

To be honest, I don't know, because it's been a long time since I got in touch with him. I don't know, I don't even feel like having this anymore, having a relationship. He lost; he lost the desire to have a relationship. (E.7).

The body gets tired. I don't feel like, you know? I had already discussed this with my gynecologist. She said it really was because of sickle cell anemia, which makes me even more tired, makes me soft. (E.14).

In the reports, it is also possible to observe that women associate loss of libido with the routine and normality of daily life. The fact that the partner has become accustomed to the lack of desire of the wife in the relations leaves them in conformity with the situation, and this leads to the neglect of the sexuality of the couple, observed in the following speeches.

I have sexual intercourse like that, normally. Every now and then I have no appetite to [...] you know? But it's normal [...] (E.4).

I think it's because of the disease that I don't feel like it, you know? But my husband got used to it. (E.5).

The pain and fatigue caused by sickle cell anemia lead to altered libido and also to the feeling of fear of losing the partner. This fact awakens the desire to fake a libido that does not exist, so that the companions do not abandon them, as shown in the following report:

I pretend. In fact, it's because, you know, I don't feel this whole pleasure as women say. And I don't have that desire, that sincere desire to have a relationship, but I have it, in order not to lose my husband [laughs]. (E.13).

Women with sickle cell anemia are unable to have a healthy sex life, and it affects their achievement as women, as can be seen in the following fragment:

Many times, I avoided having sex with my husband, because I felt more pain, you know? I felt more pain when I was having intercourse. Then I think I'm incapable. (E.18).

I feel good as a woman; I just don't feel so fulfilled because I am not willing to do it with my husband every day or at all times. I get tired; I feel short of breath, that's it. (E.19).

In the reports that compose this category, it was evident that the clinical symptoms of the disease provoke a feeling of impotence and influence the affective and sexual life of the

interviewees, thus accentuating their fragility in the face of a chronic disease that causes different marks and also their support need to achieve a better quality of life.

Support or lack of support from partners strengthens or weakens women

The support of partners and spouses received by women with SSA makes them strengthened to cope with the disease.

My husband supports me; he buys medicine if I don't have it at home. If he needs to do things, he does it. He cleans the house and organizes everything. (E.5).

[...] after he knew what it was and after I explained to him what sickle cell anemia was, he was sad, but he gives me support, and stays by my side. (E.11).

In the speeches, it is clear how much the support of the companion facilitates the daily tasks at home. Even with the sadness caused by the disease, the support leaves them more protected and confident to overcome the limitations imposed by sickle cell disease.

I have a person who takes care of me, who will not let me do any of this, you know? But he knows that, I am in crisis, when it's a very strong crisis, I have to be hospitalized. I urinate all over, you know? It's just like that; I faint, and everything. But today I feel strong, I feel I am better informed. (E.14).

Some reports refer to the companion's concern to help, and to the effort he makes so that she will have a better recovery, as shown in the following speeches:

[...] he was never a bad person; he was always nice to me, you know? When I am like this, in this phase of crisis, he also gets worried and drives me to the doctor. He did everything that was necessary for me to have a much better recovery. (E.18).

I was already sick and had crises when we started dating, you know? So he accompanies me and helps me to this day. Even today, he gives me strength... It is he who helps me in the first place; he is everything to me; he is there. (E.22).

The care of the companions with the women in facing the suffering makes them feel more confident. Their perception of the needs they present is also a factor in helping to implement this care.

People helped me in everything I did. So he found it very strange, right. And with that, his reaction was to try

to take more and more care of me. I think his love has increased even more. Because he sees my suffering, and he struggles to always take care of me. (E.13).

In the reports presented, it is apparent how the support of the partners of women suffering from sickle cell anemia is important. The fact that they need help often to perform minimal daily activities, especially during crises, makes them realize the relevance of having a partner who supports, helps, and cope with the illness along with them. This support strengthens the relationship and gives greater possibility of a lighter life and with fewer limitations.

On the other hand, the lack of support on the part of the companions, described in the following statements, reflects the other side of this relationship.

To tell you the truth, doctor, he doesn't know. He never knew about this disease. He met another woman; I don't know where he went, but he left me. [...] he never asked me why I'm going to the doctor, or why this and that. He did not ask me what I have or what I don't have and I left it be. (E.07).

Oh, he doesn't care about anything. That's right, he doesn't. He doesn't care if I take the medicine or not, or if I go to the doctor or not. He just doesn't care. He doesn't care. (E.23).

The lack of interest in the disease, for reasons not mentioned in the reports, is one of the factors that propitiate the partners' lack of support for women with sickle cell anemia. Therefore, not having a companion present in the daily struggles caused by the disease is a factor that makes the daily life of these women more arduous and causes a feeling of sadness and loneliness in them.

Discussion

The clinical manifestations of sickle cell anemia in the reproductive phase become a nuisance to the body image of women with SSA, since it is a phase characterized by arousal for affective/sexual relations. The manifestations are differentiated and can be complex if, in addition to the symptoms common to the pathology, ulcers of lower limbs and jaundice appear, which also alter the body image and, consequently, the affirmation of sexuality⁽⁹⁾.

The feeling of impotence, of not feeling sensual, besides shame, is some of the feelings experienced by those interviewed with sickle cell anemia. In SSA, as in other chronic diseases, psychosocial aspects affect the emotional and social adaptation of the people who have them throughout their lives. In the adult phase, socioeconomic problems, such as unemployment, may be present, in addition to emotional and psychological problems, including difficulties in relationships, low self-esteem and concern for death⁽¹⁰⁾.

In the case of women with complications such as leg ulcers, the issue of self-esteem may take on an even greater proportion. Young women, afflicted by this complication, have a great difficulty to adhere to treatment, as well as social life, reflected in the loss of self-esteem, decrease in sexual activity, among other aspects⁽⁷⁾.

The feeling of shame is also experienced by women with sickle cell anemia, believing that their bodies are not within the standard of beauty demanded by the media, and present themselves as bodies that are not very sensual or undesirable.

The aforementioned pains are not only associated with painful crises, which are one of the manifestations of sickle cell anemia, but are also related to the feelings caused by the disease, which mark the body and self-esteem of these women, making their living more difficult and interfering in their sexuality.

Even if a woman with sickle cell anemia is not affected by the clinical signs of the disease, or manifests complications such as leg ulcers, the non-visible marks of the disease end up reverberating and turning experiences into negative ones, since the stigmas of SSA are present at all times. As an example, there is a perception that the disease affects only the black population, which interferes with feelings of self-esteem and racial pride, resulting in anxiety, fear, apprehension, resentment, guilt, psychological disturbances, chronic frustration, especially in the way individuals interpret their illness.

Chronic diseases, especially SSA, besides presenting a characteristic clinical picture,

develop several comorbidities, including emotional ones. The physical limitations caused by PA are sources of emotional tension, which affect the vocational, educational, psychological and social adaptation of women's lives, causing suffering and interfering in various activities of their daily lives⁽¹⁰⁾.

Pain is an aspect in the lives of women with chronic illness that affects them and, most of the time, emotionally and physically destabilizes them⁽¹¹⁾. The reports of severe painful crises cause these women to limit themselves to a series of activities, as well as the sexual practice, which becomes intensely impaired, as reported by the 25 participants, among which 18 reported having pain crisis as complication.

Such difficulties are accentuated by the sociodemographic conditions of the women interviewed (black and brown people, with low educational level, mostly not included in the formal labor market and who develop manual and artisanal activities of low remuneration, with an increase in the level of family dependence, as identified in studies)⁽¹²⁻¹³⁾. Thus, many of them, even with the aggravated disease, need to continue to exercise some activity⁽¹⁴⁾.

In addition, a study showed that low schooling can negatively influence the evolution of chronic disease, due to the compromised reading and comprehension capacity of the guidelines during health education actions⁽¹⁵⁾.

Social support to women with SSA can enable the coping capacity of the disease and its complications. The support received mainly from the family can be a support capable of altering the effect of the stressors, guaranteeing them better conditions to deal with the consequences of the disease, which can directly influence the improvement of the quality of life⁽¹⁰⁾.

The support of the companions, explicit in the help of housework, in the purchase of medicine in the pharmacy, or explicit only with gestures of support, encourages in women the confidence to face the disease, since the limitations caused by sickle-cell anemia weaken them.

Depression can occur when signs and symptoms intensify, and emotional defense

resources seem to be depleted in the face of exhaustion. Continuous hospitalizations, long periods of pain, imminent death, lack of support from the partner and the family are factors that activate the feeling of impotence in women, weakening them⁽¹⁰⁾.

The hospitalizations caused by the complications of sickle cell anemia result in the withdrawal of women from daily activities. As a result, they need a support network to go through this moment without major trauma. When they do not have this support, crises can be aggravated. Therefore, support is of fundamental importance for these women to return to their family and friends, as well as their work activities, to stimulate social reintegration⁽⁷⁾.

In speeches, women talk about how powerless and incapable they feel, because they believe they cannot perform all the tasks of a wife who does not have sickle cell anemia. When they see themselves without the support of their partners, without the support of the family, everything seems more difficult, because they feel alone in the midst of difficulties. Lack of support and knowledge, in addition to negatively affecting women's emotional health, can also hurt recovery. Late diagnosis and ignorance of the disease itself by patients and their families lead us to abandon medical follow-up, worsening the clinical picture. These factors may reduce the life expectancy of these individuals⁽¹⁶⁾.

In view of the above and given the positive weight of these aspects found in this study, it can be affirmed that the lack of support of the companions, as well as of the relatives, negatively interferes in the life of the women, both in the psychological and physical aspects. The lack of any kind of support, whether psychological or concerning the clinical manifestations of sickle cell anemia and help with housework, hospital follow-up, and the purchase of medication, is detrimental to the daily life and quality of life of these people.

Conclusion

The clinical manifestations of sickle cell anemia, its bodily repercussions, and the discomfort caused by pain and fatigue compromise women's activities, their body image, and self-esteem. Such symptoms and bodily and emotional manifestations caused by the disease have repercussions on the sexuality of women with SSA. Concomitant to this, one should take into account their unpreparedness to experience bodily changes during the reproductive phase, in which the care with the body, vanity and marital relationships become more intense and deserve attention and a more specific look, due to impairment of body image, a peculiarity of sickle cell anemia.

Manifestations such as pain and fatigue are also factors that negatively affect the daily life of women with sickle cell anemia, since they are accompanied by several limitations to them, which may explain the feelings of incapacity and frustration, causing them to go so far as to pretend to have libido, so as not to be abandoned by their companions. Another negative repercussion in the lives of women with SSA is the lack of support from the partners, who do not understand the disease or what it represents for them, further weakening them.

Contrary to the situation of lack of support, when they rely on the help and care of their partners or a network of family members, women do not lose the essence of what it is to be a woman. This approach of the companion in the perspective of the care only tends to influence positively, since the woman with sickle cell anemia, in the presence of a companion that donates himself and who supports her constantly, becomes more strengthened and more disposed to face the limitations.

Therefore, in order to minimize the impacts on sexuality caused by the chronic disease, it is necessary to update the health professionals for the care directed to women with SSA so that they can provide a quality service focused on the real needs of these women.

Collaborations:

1. conception, design, analysis and interpretation of data: Aline Silva Gomes and Silvia Lúcia Ferreira;
2. writing of the article and relevant critical review of the intellectual content: Aline Silva Gomes, Nathalie Santos Moreira and Lorena dos Santos Araujo;
3. final approval of the version to be published: Aline Silva Gomes Xavier and Silvia Lúcia Ferreira.

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Received: June 29, 2018

Approved: April 23, 2019

Published: July 11, 2019



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