OBJECTIVE: understanding the experiences of women with sickle anemia and leg ulcers. Method: an exploratory study with a qualitative approach, in which participated five women, adult, met in a support group for people with sickle anemia in Salvador / Bahia / Brazil. The data were generated through semi-structured interviews, recorded, transcribed and analyzed through thematic content. The research project was approved by the Research Ethics Committee, Opinion 075/2010. Results: women participant experience severe pain, feelings of shame and worthlessness which results in pain, low self-esteem and limitations in social life. Conclusion: it was evident that the experiences of these women motivate behavior of isolation culminating in solitude and loss of the sense of life. Thus, this study points to the need for public policies those promote individual care through multidisciplinary team glimpsing full assistance. Descriptors: Sickle Anemia; Women; Nursing.

RESUMO
Objetivo: compreender as vivências de mulheres com anemia falciforme e úlceras de perna. Método: estudo exploratório, com abordagem qualitativa, do qual participaram cinco mulheres, adultas, atendidas no grupo de apoio a pessoas com anemia falciforme em Salvador / BA / Brasil. Os dados foram produzidos por meio de entrevistas semiestruturadas, gravadas, transcritas e submetidas à análise de conteúdo temática. O projeto de pesquisa foi aprovado pelo Comitê de Ética em Pesquisa, parecer 075/2010. Resultados: as mulheres participantes vivenciam dor intensa, sentimento de vergonha e de inutilidade o que se traduz em sofrimento, baixa autoestima e limitações na vida social. Conclusão: evidenciou-se que as vivências dessas mulheres motivam o comportamento de autoisolamento culminando em solidão e perda do sentido da vida. Assim, este estudo aponta para a necessidade de políticas públicas que promovam o cuidado individual através de equipe multidisciplinar vislumbrando a assistência integral. Descriptores: Anemia Falciforme; Mulheres; Enfermagem.

RESUMEN
Objetivo: comprender las experiencias de las mujeres con anemia falciforme y úlceras en las piernas. Método: estudio exploratorio con enfoque cualitativo, en el que participaron cinco mujeres, adultas, atendidas en un grupo de apoyo a personas con anemia falciforme en Salvador / Bahia / Brasil. Los datos se obtuvieron a través de entrevistas semiestructuradas, grabadas, transcritas y analizadas por el contenido temático. El proyecto de investigación fue aprobado por el Comité de Ética en Investigación, Opinión 075/2010. Resultados: las mujeres participantes experimentan dolor severo, los sentimientos de vergüenza y falta de valor que se traduce en sufrimiento, baja autoestima y las limitaciones en la vida social. Conclusión: es evidente que las experiencias de estas mujeres motivan el comportamiento de autoaisolamiento culminando en la soledad y la pérdida del sentido de la vida. Por lo tanto, este estudio apunta a la necesidad de políticas públicas que promuevan la atención individual a través del equipo multidisciplinario vislumbrando una asistencia integral. Descriptores: Anemia Falciforme; Mujeres; Enfermería.

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INTRODUCTION

Sickle cell anemia (SCA) is a genetic disease caused by variation in hemoglobin, red blood cells responsible for transporting oxygen to the tissues. It is the most common and severe type of sickle cell disease, characterized by the presence of hemoglobin S in homozygous. With clinical manifestations usually from six months of age; it can present complications throughout life, requiring regular monitoring with a health team.1

The most accepted hypothesis is that the hemoglobin S gene mutation that causes sickle cell disease emerged in Africa thousands of years ago. During the period of slavery, with the forced diaspora of Africans, occurred the dispersion of the S gene to other parts of the world. Even today, this type of variant hemoglobin is more prevalent in regions with high concentrations of black population.2 In Brazil, it is estimated the birth of 3.500 children with sickle cell disease per year, with national average incidence of 1 per 1.000 live births.3 In Bahia, from the neonatal screening between 2007 and 2009, were identified 966 cases of sickle cell disease, of which 41% had the SS genotype, the called AF.4

The disease can cause several complications such as chronic anemia, severe infection, episodes of acute pain, growth and sexual maturation delay, stroke, among others. From adolescence highlights the emergence of malleolar ulcers are difficult to heal, especially in males over the age of ten years old. The leg ulcers are frequent complications associated with AF, occurring between 8% to 10% of homozygous carriers.5 6 Its etiology is still unknown, differing from ulcers secondary of diseases such as diabetes, venous insufficiency, among other.7

In cases where there is healing, the process can be sixteen times slower compared to ulcers of venous ulcers. It is estimated that 97% of these lesions may become refractory to treatment after periods ranging from one to six years.5 The appearance of ulcers depends on factors such as vascular occlusion, tissue hypoxia and hemolysis. Its onset may be spontaneous or resulting from trauma, such as an insect bite.5 9

In the healing process is essential rest and elevation of the affected limb to appropriate therapy.6 Young people affected by this complication have great difficulty adhering to treatment, as well as to social life, reflecting the loss of self-esteem, decreased sexual activity among other things.

This study aims to understanding the experiences of women with leg ulcers secondary to sickle cell anemia, demonstrating through speeches how to live with the wound, which strategies, care and difficulties present in their trajectories. It is highlighted the relevance of the work given the need to give visibility to the reality experienced by people who have the disease, contributing to scientific literature on the theme. It is expected to bring significant information about the life of these women, sensitizing professionals and contributing to the improvement of care and care dispensed.

OBJECTIVE

• Understanding the experiences of women with leg ulcers secondary to sickle cell anemia.

METHOD

This is an exploratory study of a qualitative nature, conducted in May 2010, with five women who met the following inclusion criteria: being an adult, present AF and leg ulcers. No exclusion criteria were established.

The approach with the participants took place in the meetings of Bahia Association of People with sickle cell disease (ABADFAL), scheduled monthly to discussing topics chosen by the women themselves. These meetings made up the invitation and objectives of the research were presented, those who expressed interest in participating signed a consent form authorizing the data collection.

The data were produced by individual semi-structured interviews in a private environment of the association. The women answered questions such as: Tell me how is living with the wound; Describe how your day to day is with the wound; How do you feel about it? How do you maintain your daily activities?

The interviews were transcribed and analyzed by thematic content modality which occurred in three sequential steps: a pre-analysis which consists of comprehensive reading of data with the goal of establishing first impressions on the content and extract the thematic units; exploitation in which it grasps the issues highlighted in the statements systematizing them; and, finally, the interpretation step that adds inferences and conclude the analyzes relating them to the theoretical framework.10

Looking to preserve the identity of the participants, fictitious names were assigned in the presentation of the statements. It is noteworthy that this study followed the recommendations of Resolution 196/96 in all its stages and was authorized by the Ethics Committee of the Catholic University of Salvador under protocol number 075/2010.
The study included five adult women aged between 27 and 35 years old, with a confirmed diagnosis of AF and leg ulcers. All women interviewed declared themselves black. Among the economic classification, the low-income prevailed without gainful activity, carry their own dressings at home, with sporadic trading in these health units. Only two of them reported having a steady partner, the other declared unmarried, living with family.

The reports reveal that the first lesions appear during adolescence, they are described as a small sore that increase in size, few come to the healing and have frequent recurrences. The permanence of the wound may be so prolonged that sometimes accompanies these women throughout his youth, causing pain, interfering with social contacts, changing their self-image and sociability.

Looking to live a life closer to the "normal", women reveal how they behave to move forward with their lives, despite the limitations that are to take care of themselves, work, perform household chores. We also observed a strong tendency to self-isolation:

I try not to think about the disease. [...] I walk mostly alone, I'll see the ocean, not like shopping because a lot of people. I like a quieter place. I am sometimes angry with life; sometimes cry a lot, if I keep thinking on the disease is worse. If I keep thinking about it, I'm even more depressed. (Latifa, 27, injured since 14).

The experience of pain is not unique to situations where the sores are present, since acute painful crisis is the main reason for hospitalization of people with AF. The difficulties arising from the pain accumulate the other related to the existence of wound care requires a daily irritability, caused frequently in these women.

I have trouble getting me difficulty to make my activities, walking, taking care of my son, a lot of pain [...]. Because pain is very strong, very much. Sometimes for me to dish washing I wash sitting, make a porridge, a meal, I was sitting all, because I cannot stand. [...] The pain prevents you from doing anything, all activities from home. I feel more pain when I wake up in the morning, getting out of bed is very hard. [...] When I'm feelin pain is too much pain, I get very nervous, sometimes I get so nervous that ends in reaching those who have nothing to do. (Yaa, 33, injured since 17)

The study participants tend to adopt different strategies to deal with pain; it is common among them mute themselves avoiding that the pain bothers other people close to them:

I feel sad, because I think the pain bothers someone, I do not like talking with my family when I have pain, only when the pain is unbearable. When you do not pass, then I'll talk to my mother [...] she likes to do some teas, some natural thing, if not resolved, go to the health post. I do not like to be bothering my family with the symptoms of my illness. (Akilah, 27 years old)

Among the respondents, 100% reported use of common painkillers too, when affected by high levels of pain; however, none of them said to be guided by any measurement scale of this symptom, denoting that receive little or no information on this issue.

 [...] When the ulcer is infected and very extensive, I take a pack of dipyrone per day, two pills, but it is not solving my pain. (Yaa, 33)

I take when I feel pain, paracetamol, dipyrone, diclofenac sometimes, because the leg pain is very strong. [...] What bothers me most is the disease in the leg. Sometimes I cannot sleep at night, the pain "empath" sleep. 've Been up all night and went to sleep only 05h in the morning, and having to wake up at 07:30 (Latifa, 27)

Pain interferes in social life, and even when it is not present, the fear that makes daily activities, or recreation to bring back, along with the reappearance of the wound.

Now, when I'm in pain, when it begins to opening, I do not go nowhere, anywhere even'm asking someone to buy something in the market, when the ulcer is very open, I cannot do anything anyway. I have no pleasure, I have no social life. When I'm better, I'm not leaving, afraid to open again. My life is at home, if I walk, if I walk, starts to open again. And when it starts to get worse without me doing anything to open, I do not go out because of the pain. (Yaa)

The fear of being discriminated for having wound is ruled by negative experiences for them at some point in their career, and especially by the expectation of revulsion and fear of contagion that secretions and odors cause wounds on them and in others.

I remember a fact even in secondary school, I think I was born there, I was in the last year, I went with a leg wound, I went with pants, but it showed me. The bandage, do
not know, I think a little bit wet and it showed me. People began to notice and walked away; I think there was born this trauma. I do not think I solved it today. I was sitting at the table in the courtyard; one person noted, did not say anything and took the book from her boyfriend. (Akillah)

Also, when “with” pants on the street to go to the mall, is slathering, then I have to go to the bathroom all the time, change the bandage. For example: I go to the mall with my boyfriend, when he gets halfway slathering gets his pants, that are what bothers you. (Ayo)

People who have body scarred or injured tend to social exclusion as a result of odors and low self-esteem that produce wounds. Moreover, the constant use of dressings hinders the guise that such people both strive to maintain.

Neighbors know that I have something in my leg, but do not say anything. I'm not getting much commenting. A neighbor once asked: What is this? She knows I have sickle cell anemia. People feel disgusted to get close because of the injury. Due to illness, and with the leg ulcer, I feel different from other people. (Areta)

To avoid public questioning, women adopt a discipline and self-monitoring on their bodies, change their dress, adopting the use of trousers or long skirts to hide their bandages and sores look oblivious. It seems to be more difficult to talking about the ulcer than about other consequences of the disease.

Only ride on pants all the time, only take off to sleep. If I get a visit, I'm on pants, I'm on pants at that. Where I live is a very busy avenue, a lot of people, and my house is just the opposite. So everyone that passes sees me, I get pants the whole time, just take off to sleep when I close my door. My whole family knows, the neighbors know, because it was defective, since atrophied, was already disabled, right? Sometimes you see that I have disabilities but do not know that I have ulcers. (Yaa)

Discrimination and neglect are also perceived in the contexts of health services, spaces where it's supposed to find professionals ready to meet the demands of people with AF. In these situations, women with sickle cell anemia may react with aggression or express unresolved frustrations: I got tired, I went to the emergency [...] the doctor said thus: Ah! She is addicted to the medication. He asked what medication I was taking. I answered: Who has to know it are you. [...] The doctor here is lord (Areta)

Among the situations that are most uncomfortable to women with AF, there is an emphasis on the pain. However, leg ulcer adds more factors involving painful events, such as the need for daily handling damage during cleaning and dressing, daily small traumas on the leg involved the use of covers which promote adhesion and hinder its removal. Moreover, this suffering links to the negative feelings and the assistance provided by health professionals.

Painful experience due specifically to ulcer is so intense that people affected tend to not step correctly during walking, in search of a less painful position during gait. Consequently, those people develop muscular atrophies which modify the gait and deform the foot, featuring the so-called equinus foot, making the brand of difference still more visible to the other people.11

To the extent that the frequent use of analgesics seems no longer to take effect against the pain, women tend to self-medicating, which may lead them to risk of poisoning or dependence. To avoiding this, an alternative use for them is to try to get used to the pain, adopting behaviors of bed restriction, avoiding mobilization until the pain reaches tolerable thresholds since become aware that the pain will be persistent.

People with AF adults between 18 and 44 years old have more episodes nociceptive according to a study in the UK, as well as long-lasting crises, whose average is 6 days. Another important issue concerns to the fact that the most frequent location of pain to be the bottom of the knee and lower leg, which also often ulcers usually appear.12

Studies indicate that people with wounds seek for help to controlling pain and normalizing their lives, but receive little or no attention from healthcare professionals and few receive adequate analgesia.13-14 People with injuries and constant pain can have their symptoms overlooked by professionals and are labeled “poli-complained”11,15

A study in London showed that people with AF show up suspicious and perceive themselves discriminated by health professionals by constantly seek services to remedy their painful crises, and that such act devaluing their complaints and linking them to stereotypes of people drug dependent.14

Black women with AF, when joining in healthcare institutions experience discrimination of racism, these scenarios professionals depreciate and invalidate them the importance of their social and cultural codes, disqualifying the experiences, which, when reported, are seen as a untruth.16 This behavior causes the same feel devalued and

DISCUSSION

Among the situations that are most uncomfortable to women with AF, there is an...
diminished and possibly contributes to increased pain perception.\textsuperscript{16-17}

It is essential a multidisciplinary care about nociceptive events in AF since it has been demonstrated that adults with the disease rarely experience thresholds classified as 0 (zero) on the scales of measurement of pain.\textsuperscript{11} It is important to the broad approach of the multidisciplinary team, assessing biological, cultural and psychosocial issues surrounding the painful events that are magnified when leg ulcers affect this population.

Recognizing themselves as different from the others through the signs of illness such as AF and ulcer, those situations that leave visible marks on the body, these women lead to the feeling of constant shame. This feeling is experienced in all public situations where such women need to expose such ulcers, or the changes that it causes as different floor, limp, unable to undress completely on the beach, having to inform about their problem to the curious who question them. The feeling of shame is experienced not only when such things happen, but when it is anticipated that they may occur.\textsuperscript{18-19} Thus women also anticipate their attitudes avoiding the fact that shame happens. Thus, shame provides isolation and social exclusion, restricting relations to family, health professionals, and or others with the same problem, because they believe that will be well understood and not discriminated.

CONCLUSION

Women with AF have their living impaired by the appearance of leg ulcers, as these impose new skincare routine, which also act as stimuli to further episodes of pain. In this sense the experience of living with AF, aggregate negative feelings that intensify suffering, since the negative connotations those accompany ulcers cause social exclusion.

The pain associated with leg ulcer stands out as an important source of suffering to these people. It is considered of fundamental relevance of this pain the management, in order to reducing this suffering. Thus highlights the importance of considering issues relating to analgesia as an integral part of education for self-care. In this sense, the strong and continuous pain associated with wound, requires that people who have leg ulcers have knowledge of topics such as pain assessment and combined use of drugs, so that they can enhance pain management at home, minimizing the painful experience as well as avoiding potential risks of poisoning by improper use of medications.

Health professionals have constant contact with people with ulcers resulting from AF. It is important that this dialogue becomes free of censorship and discrimination from professionals, who should be prepared to know and understand the experiences of people with AF. Postures to label the person with the disease as “sickle cell patient”, for example, should be avoided, as they bring history of prejudice and are stigmatizing; thus, resulting in a gap between the person with AF and the multidisciplinary team, disadvantaging the service friendly and democratization assistance.

Therapeutic Listening is configured as an essential care to this population. Another highlight is the incentive to enter into association with the disease as an important opportunity to connect with other individuals with the disease, encouraging the sharing of experiences, mutual growth and the strengthening of social control, a key element to advance public policies and appropriate assistance.

An interdisciplinary and holistic approach can advance to identify social, cultural, and psycho-emotional aspects involved in this experience; thus, enabling a full and comprehensive care those exceeds the biological dimension of these women.

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REFERENCES


Women with sickle anemia living with...