

FROM OVERPROTECTION TO STIGMA: FAMILY RELATIONS OF PEOPLE WITH LEG ULCER AND SICKLE CELL DISEASE

DA SUPERPROTEÇÃO AO ESTIGMA: RELAÇÕES FAMILIARES DE PESSOAS COM ÚLCERA DE PERNA E DOENÇA FALCIFORME

DE LA SOBREPOTECCIÓN AL ESTIGMA: RELACIONES FAMILIARES DE LAS PERSONAS CON ÚLCERA DE LA PIERNA Y ENFERMEDAD FALCIFORME

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Objective: to grasp the perceptions of the sick with leg ulcers and sickle cell disease about family relationships in chronic illness. Method: exploratory, qualitative, descriptive-type study with five people with leg ulcers secondary to sickle cell disease. Data were obtained in interviews and submitted to thematic analysis. Results: people with sickle cell disease and ulcers perceive the dedication and care received from family members to maintain a treatment routine, but assess that these family members overprotect and limit their living condition due to fear of death. On the other hand, people with this disease are mistreated by family members who do not understand the limitations caused by the disease. Conclusion: the sick with leg ulcers and sickle cell disease attribute importance to family members in coping with the adversities promoted by the disease, as well as highlight that the family is a source of ill-treatment, which reinforces feelings of uselessness, due to the dependence on care and discrimination suffered.

Descriptors: Family. Anemia, Sickle Cell. Leg Ulcer. Social Stigma. Chronic Disease.

Objetivo: apreender as percepções dos adoecidos com úlceras de perna e doença falciforme acerca das relações familiares no adoecimento crônico. Método: estudo qualitativo exploratório do tipo descritivo com cinco pessoas com úlceras de pernas secundárias à doença falciforme. Os dados foram obtidos em entrevistas e submetidos à análise temática. Resultados: pessoas com doença falciforme e úlceras percebem a dedicação e o cuidado recebidos dos familiares para manutenção de uma rotina de tratamento, mas avaliam que esses familiares superprotegem e limitam a condição de viver devido ao medo da morte. Em contrapartida, as pessoas com essa doença são maltratadas por familiares que não compreendem as limitações da doença. Conclusão: os adoecidos com úlceras de perna e doença falciforme atribuem importância aos familiares no enfrentamento das adversidades promovidas pela doença, bem

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como destacam que a família é fonte de maus-tratos, que reforçam sentimentos de inutilidade, pela dependência de cuidados e discriminação sofrida.

Descritores: Família. Anemia Falciforme. Úlcera da Perna. Estigma Social. Doença Crônica.

Objetivo: detener las percepciones de los enfermos con úlceras de la pierna y enfermedad falciforme sobre las relaciones familiares en enfermedades crónicas. Método: estudio cualitativo exploratorio de tipo descriptivo con cinco personas con úlceras de la pierna secundaria a la enfermedad falciforme. Los datos se obtuvieron en entrevistas y se sometieron al análisis temático. Resultados: las personas con enfermedad falciforme y úlceras perciben la dedicación y la atención recibida de los miembros de la familia para mantener una rutina de tratamiento, pero evalúan que estos miembros de la familia sobreprotegen y limitan la condición de vivir debido al miedo a la muerte. Por otro lado, las personas con esta enfermedad son maltratadas por familiares que no entienden las limitaciones de la enfermedad. Conclusión: los enfermos con úlcera de la pierna y la enfermedad falciforme conceden importancia a los miembros de la familia para el enfrentamiento de las adversidades promovidas por la enfermedad, así como destacan que la familia es una fuente de malos tratos, que refuerzan los sentimientos de inutilidad, debido a la dependencia de la atención y la discriminación sufrida.

Descritores: Família. Anemia de Células Falciformes. Úlcera de la Pierna. Estigma Social. Enfermedad Crónica.

Introduction

Sickle cell disease (SCD) is genetic and chronic, considered a public health problem due to its prevalence in Brazil and worldwide, with a high rate of morbidity and mortality and several complications resulting from the disease⁽¹⁾. The term SCD encompasses a group of hereditary hemolytic anemias that have in common the presence of hemoglobin S (Hb S) within the red blood cell. The presence of Hb S alters the conformation of the red blood cell and triggers a series of organic dysfunctions that will affect the activities of daily living of the sick⁽²⁾.

The SCD has a social aggravating factor due to its magnitude and transcendence, since most individuals with SCD belong to the most economically disadvantaged layers. This situation is aggravated by the several limitations that the disease imposes, such as unemployment and low schooling. Associated with this, SCD was brought with the process of forced immigration of enslaved people from Africa to the Portuguese colonies of America. It is more prevalent in regions that received and has the prevalence of Africans during this period.

It is estimated that, in Brazil, there are more than 8,000 people with sickle cell anemia and about 2 million people with the Hb S gene⁽³⁾. Bahia is the state with the highest number of

Afro-descendants and has the highest prevalence of the disease in the country, reaching rates of 5.5% of the population⁽⁴⁾.

Leg ulcers are the most common cutaneous manifestation of SCD and can be a chronic and debilitating condition, negatively influencing quality of life⁽⁵⁾. These very painful lesions still arise in youth. They usually become chronic and resistant to the therapies used, with high recurrence rates after healing⁽⁶⁾.

The person with SCD faces a triggering experience of great psychological vulnerability not only because it is a potentially disabling disease, but also because its therapeutic trajectory often induces stigmatizing changes in body image, such as the appearance of leg ulcers, which have repercussions on self-esteem and the identity of the sick subjects. The limitations and physical repercussions of SCD visible in the body can lead the sick to enter a stigmatizing process. Social stigma is defined as a condition of the individual who is unable to full social acceptance⁽⁷⁾.

SCD is a condition that can generate several changes in people's lives, with repercussions on social interactions, marital and family relationships, education and employment⁽⁹⁾, especially when associated with leg ulcer⁽⁸⁾.

Leg ulcers are present in 8% to 10% of people with SCD and homozygous patients. There are reports of an incidence above 50% in patients living in tropical areas⁽⁹⁾.

Living with the patient with a chronic disease and perceiving his/her physical and psychic suffering allows the reflection that this condition brings a series of changes in the life not only of the sick, but also of their relatives, who are often unprepared to understand all aspects that involve the problem, which requires coping strategies before the new situation⁽¹⁰⁾.

Changes in interpersonal relationships of individuals with SCD are aggravated when they present another chronic complication associated with the underlying disease, such as leg ulcers secondary to SCD. Changes in family relationships can negatively interfere in interpersonal relationships between family members and cause a series of complications for both the sick and family members. Therefore, it is necessary to acquire coping strategies to minimize these complications, as well as to intervene positively in the rehabilitation process of the individual who has the chronic health condition.

SCD causes significant impacts on the lives of the sick individual and his/her family, either considering the moment of diagnosis or by involvement in the entire care process⁽²⁾. The changes that cause repercussions on the family relationship can intervene positively or negatively in the rehabilitation process of the individual. Thus, a good family relationship is of great importance in the conditions in which people experience chronic diseases, because family members can strengthen the sick person to cope with the disease.

Although the theme sickle cell disease (SCD) has been researched in Brazil, the high prevalence of SCD, as well as the high rate of morbidity and mortality resulting from complications imposed by the disease, as mentioned, are factors that promote the need to understand how the daily life of family members and people with leg ulcers secondary to SCD is revealed daily. In view of the above, the relevance of this study is manifested by the possibility that the object

in question is discussed in the academic and scientific environment, in order to elucidate which difficulties family relationships face in chronic illness from the perspective of people with ulcer secondary to SCD, as well as to promote care embracement practices that contemplate the individual in biological, social and psychoemotional dimensions.

The justification of this study includes the need for nursing professionals to understand the family relationships of people with SCD, to support care actions and attitudes committed to the sick and their family, as well as strengthen the bonds in the care process and coping strategies.

The object of investigation of the present study is "Family relationships of people with leg ulcers secondary to SCD". This study is based on the following question: How are family relationships in chronic illness perceived by patients with ulcers secondary to SCD?

The study aims to grasp the perceptions of the sick with leg ulcers and SCD about family relationships in chronic illness.

Method

A qualitative, exploratory, descriptive-type study was developed in a Reference Center for the care of people with SCD, located in the state of Bahia. The study included people who met the following inclusion criteria: being an adult, diagnosed with sickle cell disease and presenting leg ulcer. The exclusion criterion used was to report pain at the meeting. The sample participants were chosen by convenience, selecting the most accessible members of the population.

Data were collected from October to November 2016. The researcher's approach with the study participants occurred during previous visits to the reference service, where follow-ups were performed on leg ulcer dressings performed by the unit nurse. During this approach, the participants were approached regarding the interest in participating in the study. At the time, information was provided about the objectives, risks, benefits and relevance of the study.

All five patients who were performing dressings weekly in the referral unit agreed to participate in the study, without refusals. The meetings were scheduled according to their availability and of the first author. The average duration of the interviews was 15 minutes. The first author and researcher, during the data collection period, participated at the Center for Studies of Health Inequalities (NUDES) of the Universidade Estadual de Feira de Santana (UEFS) as a scientific initiation scholarship holder, and is currently a Master's student in Nursing at this university.

Data collection occurred through the application of semi-structured interviews, recorded and later transcribed by the interviewer, conducted in a restricted environment (the unit's nursing office), in the exclusive presence of the interviewer and the participant.

Participants were presented with the opportunity to listen, review, modify or add content and/or any information, but none of them wished to do so. The theoretical saturation of the study occurred upon identifying that the data obtained started to present redundancy and the main objective of the study was achieved.

An interview was previously conducted to validate the data collection instrument (pilot test), aiming to adjust the questions and avoid dubious interpretations, which could compromise the acquisition of reliable data. However, no readjustment was required during the study.

A semi-structured guide was applied with elements that allowed knowing the sociodemographic profile of the sick and their families and the following guiding questions: How do you see the family's relationship with the person who has leg ulcer and SCD? How are family relationships with the sick person after the appearance of ulcers secondary to SCD?

The data were submitted to reflective thematic analysis. Initially, there were the familiarization, transcription, exhaustive readings and re-readings of the data set. Then, the grasped aspects were codified in the semantic and conceptual reading of the data. Each code was revised, seeking to identify the existence of themes, observe

the pattern and coherence between the codes, thus performing the grouping. The review of the themes sought their refinement. Finally, the themes were defined and named and the writing of the results was elaborated⁽¹¹⁾. No program was used to manage data. Field diary records were made regarding the emotions demonstrated by the participants during data collection.

In order to preserve the participants' identity, in this text, they are identified by the letter I (interviewee) followed by a number indicating the order of the interview. Example: (I1).

This study was guided by the quality protocol of qualitative studies Consolidated Criteria for Reporting Qualitative Research (COREQ). Regarding ethical aspects, the recommendations of Resolution n. 466/2012 of the National Health Council were followed at all stages. This study is linked to the research project entitled "Body representations and Sickle Cell Disease: Repercussions on Everyday Life, Care and Sexuality", approved by Opinion n. 1.440.239 and Certificate of Presentation of Ethical Appreciation (CAAE) 49493315.3.1001.0053.

Results

Five people with leg ulcers secondary to SCD participated in this study. The sociodemographic characteristics analyzed originated from the groups of variables: identification, gender, age, education and occupation. The results showed a higher concentration of users from 30 to 40 years of age; males; incomplete high school; Protestant religion; black race/color. All study participants were unemployed. The grasped themes are presented below:

Family relationships marked by zeal and concern

People with leg ulcers and SCD experienced clinical manifestations that required strict care routine and frequent visits to health units for pain management, blood transfusions and consultations, as evidenced in the following statements:

Seeing it causes so much suffering, nights and nights without sleep, crises and crises, hospitalization. It is too hard for me to face it. (11).

The participants perceived that their families developed with them a harmonious relationship of care and sought to offer them well-being. These relationships were marked by feelings of zeal, concern and overprotection from family members to the sick, as evidenced in the following statements:

My aunt who lives with me is always worried and says, "Oh, why '13' keeps going out, getting home late!" And it is normal. (13).

The study showed that the family relationship helps coping with SCD and leg ulcer, when the sick receive care, affection and attention and when they see in the family a support to face the difficulties found in the trajectory of illness. It was also evidenced that the care provided by family members, such as providing food at scheduled times, promoting tranquility in allergic crises and dressing of leg ulcers, provided family relationships considered good for the sick:

The relationship is good. Because there is that care. It prevents me from doing anything that could harm me even more. They support me. They do not allow me to work, make an effort. When I want to do anything, they tell me to care for myself. The relationship is great! In general, it is great [...] But at home they are usually used to it. (12).

No problem in my family, thank God. Everybody treats me well. (13).

She makes my juice at the right time, my food, treats me very well. When I am nervous, feeling pain, she gives me affection, sometimes she cries along with me in difficult times. She is the person, she is my wife and my family I have. She has no prejudice to say she is leaving me or something. We live everything in peace, we pray together, we walk together. She has no prejudice against me, she has never had, and does not have. (14).

The participants perceived attitudes of concern and overzealousness, attributing such behavior of family members to the fear of their death, especially when the family already had a history of loss of one of the members with the same disease, as reported below:

So, it is because I had other siblings with sickle cell anemia. I am the middle one. So the two younger ones died due to sickle cell anemia [...] since I was little, my parents were always very alert, very worried [...] they become too nervous. Very sad, especially my mother, who lost two children. My mother is worried about me after

losing two children. She does not want to lose another one. That is the constant concern. (12).

At the same time that zeal is understood by the sick as manifestations of affection and care, at other times, such attitudes were perceived as overprotection that limited their freedom, prevented them from making important decisions, which supposedly would bring them satisfaction, such as working or hanging out with friends. Thus, the care directed to them by the family motivated contradictory feelings, sometimes of satisfaction, sometimes of discontent.

Family conflicts that evidence the stigma and its consequences

One of the problems that caused conflicts in family relationships was related to the financial expenses resulting from the care of the disease and leg ulcer. Added to this was the manifestations and complications of the SCD, which caused physical limitations, making it impossible for them to work and contribute to the family's financial expenses, as can be seen in the following fragments:

[...] sometimes it is because I cannot do the house chores, contribute with something I could. (11).

We often feel unable to do anything, feel useful [...] preventing you from doing certain things [...] Then you start to worry if you are encumbering them. Then you just keep limiting yourself until you get a boyfriend, get married and everything. Because you are not going to be as agile as a normal person. Due to ulcers, you are unable to do many things, home activity, taking care of children. (12).

[...] then I had to stop working and it got harder. (13).

It is very distressing. You are always distressed. It affects you in all areas [...] I do not have an income, I want to get a job, it is hard to get one. We often feel unable to do anything, feel useful. (12).

Then they think it might be, "Oh, I do not think it is so hard to have this wound paralyzing like that, you have to change, you have to do it". I get so outraged! (11).

Thus, the lack of understanding about the clinical manifestations and complications of SCD in the body of the sick caused conflicts, which were often expressed in the discredit of their narratives of pain and tiredness and through the collection of daily activities and responsibilities

that the sick person performed before the appearance of leg ulcer, as can be seen below:

And they [family members], sometimes understand and sometimes do not. They say I have a soft body, that I let the disease take over me, that I do not get up. Every once in a while, it creates some problem, some strife, something. (11).

They disdain [the disease], they think I feel this problem because I want to. I think they think so, that I do not know what is going on in their minds. Do they ever think that one day they might suffer too? It might not be that way, but otherwise, but also suffering? (14).

A little bashful in this case is when the woman takes advantage of him, stepping over the guy, to undo, making joke, undoing the guy, because she thinks we are not able because of the problem, making little games, kind of annoying. (15).

The following statement shows that the misunderstanding of family members about the limitations caused by the disease to the body of the sick led to intrigues and contentions in family relationships, in which the prejudice, criticism and derogatory nicknames attributed by them were manifested:

My mother, my brothers, my uncles, they mistreat me a lot! Even after I got married, I am still mistreated by them. Not all. There is always that one who is different from the others. Then you do not treat me with respect, as I respect everyone. And when I get there, they treat me that way, like a thief, a tramp, a disease leftover, a death leftover, a bobo. Then I say: "Do you ever think that you might have a child or a relative with it one day?" I hand everything to God and turn away. (14).

These experiences culminated in the suffering of the sick, who tended to experience feelings of worthlessness, shame and distress. The feeling of shame was associated with the fact that the person with SCD and leg ulcers needed help to perform some care, such as changing the dressing or cooking, as evidenced in the following statements:

Sometimes, I feel very ashamed of being carrying a wound inside my feet. I am ashamed of my family, of everything, of the ulcer, of sickle cell anemia, knowing that I have a cureless disease [...] (11).

She [wife] treats me very well, cooks for me very well, sometimes I feel ashamed that she has to do things for me. Whenever possible, she washes, she makes the dressing. I feel like: "Sometimes I feel ashamed, a little ashamed to go out with you, you are so well dressed, so beautiful and I am behind you, limping." Then she says, "My son, never think that about me with you." Then she hugs me, kisses me, gives me affection. Then I am very proud to live this life I live today. (14).

What has changed is that we still feel a little embarrassed about things, we no longer feel at ease at home. (15).

Family conflicts around the chronic illness of one of the members were caused by changes in roles and the diversion of resources previously destined to the maintenance of the family, to pay for medications, coverage, in addition to daily trips to units for consultations and dressings. These conflicts were aggravated by the fact that the person with leg ulcer was dependent and limited to paid work and could not contribute economically to these expenses.

The way the conflicts and demands on the person with SCD and leg ulcers was evidenced signaled the existence of stigma related to the disease and wound that, in addition to exposing the person to continuous pressures to correspond to a social expectation of normality from the family, implied the emergence of feelings and emotions related to devaluation and adherence to the depreciation imposed on him/her with consequent anticipation of the stigma revealed in the feeling of shame. Such evidence is also found in the following statements:

And they [family members] are unable to accept or even do not want to accept [...] They say they accept it, but they do not [...] (11).

All this concern gets you limited, or even excluded, both emotionally as professionally. (12).

They ask you to go somewhere, and we do not go; asks us to go for a walk, and we do not go, because we are not feeling well. This changes everything. (15).

Discussion

Family support is essential for solving difficulties and problems found during chronic illness. However, this study also showed that excessive care might cause in the sick subjects the feeling of loss of freedom and autonomy to manage their own lives. Individuals with SCD since childhood are overprotected by parents and caregivers through demonstrations of love or concern, due to lack of knowledge about the disease or because they do not understand the aspects of the disease⁽¹²⁾. This study also identified that this care and zeal from family

members had repercussions on the well-being of the sick subjects.

People with leg ulcers secondary to SCD suffer the psychosocial impact of these chronic wounds in their daily lives. Pain caused by the ulcer is a factor that interferes with physical function, sometimes being avoided or restricted, and in social relationships, because pain can make it impossible to socialize, preventing the person from playing sports, leisure and going to events⁽¹³⁾.

When reporting overzealousness from family members, the participants revealed their discomfort. The surveillance behaviors of family members are constructed in the experience with the sick, while assisting the complications that threaten their lives. The fear of death is greatly reinforced in the family's imaginary, due to the great risk presented by the SCD, in the first years of the child's life⁽¹⁴⁾.

The overprotection directed by family members to the sick appears as an attitude anchored in the fear of loss, by the expectation of death or experience of previous losses. This finding corroborates a study that identified emotional needs presented by the families of people with SCD, represented by the fear of death, always remaining in a state of alertness, similar to that observed in the context of other chronic diseases⁽²⁾.

The perception of the loss of freedom can cause dissatisfaction and motivate people who are not used to transgress norms, to feel free, or to reinforce the feeling of difference and to retract, assuming self-exclusion. Young people affected by this complication have a great difficulty in adhering to treatment, as well as to social life, reflecting the loss of self-esteem, decreased sexual activity, among other aspects⁽¹⁵⁾.

The appearance of ulcers significantly compromises the quality of life of the affected subject, due to reduced muscle strength, functional capacity and range of motion⁽¹⁶⁾. This study identified that these challenges had the consequence of job abandonment and leisure deficit, awakening, in the sick, the feeling of uselessness to face the social and economic demands of the family unit.

The difficulties of daily life and eventual conflicts are aggravated by the process of illness that causes, for family members, a significant burden of care and causes, in the sick, feelings of less value, guilt, insecurity, fear, pessimism and social isolation⁽¹⁷⁾. The course of SCD, although different from person to person, is often disturbing and can be stressful for the whole family⁽¹⁸⁾.

In this study, family conflicts could be related to the financial expenses resulting from the disease process, to the detriment of the allocation of resources for the maintenance of the family, as well as to the fact that the person with leg ulcer secondary to the SCD had limitations that had repercussions on their ability to work. In this respect, it corroborates the result of a study in which the family members were also financially and emotionally burdened⁽¹⁸⁾.

Another aspect present in the SCD is stigma, which involves a type of labeling with negative consequences for individuals on whom the condemnation falls⁽¹⁹⁾. In this study, the discredit reported by the sick was mentioned as a lack of understanding. People with SCD have their experiences of pain devalued or discredited by other people, who attribute labels of weak, lazy and who pretend to be sick⁽²⁰⁻²¹⁾.

The presence of the ulcer hurts self-image, evokes the feeling of shame and affects the quality of life of individuals, requiring greater family care and greater multidisciplinary coverage^(15,22). In the present study, the feeling of shame was also triggered because the sick need help in performing daily care, such as the change of dressings. There was also a greater charge from family members regarding the fulfillment of daily activities by people with SCD due to the lack of knowledge about the consequences of the disease.

This study identified that, during the conflicts, discrimination, attitudes of depreciation, application of pejorative nicknames and insults from family members themselves emerged, which is configured as an application of stigma⁽²³⁾. People with SCD are treated as if they had a physical or cognitive disability, which implies

the inability to achieve goals and life milestones, as well as also suffer stigmatizing experiences in intimate relationships, due to complications of SCD, such as pain, priapism and late puberty, which impairs their sexuality⁽¹⁹⁾.

The health-related stigma has become increasingly an important public health problem that has received attention, as stigmatization increases the burden of affected individuals and families, especially when it comes to SCD⁽²⁴⁾. Whether in the family context or in health services, people who have SCD can be stigmatized for several reasons, such as race, disease status, socioeconomic status, growth retardation and puberty and/or chronic and acute pain that require treatment with opioids⁽²¹⁾. When the wound arises, the sum of the violence suffered and bodily changes can lead people to their own anger of grieving processes. In this phase, aggressive behaviors tend to surface and be directed to both family members and close people as healthcare workers⁽²⁵⁾.

The feeling of uselessness is reinforced in this study with the lack of productive activity, employment and scarce conditions to contribute financially with their own care. It is believed that it is necessary to create public policies in order to reduce the difficulties in coping with the disease, through social and psychological monitoring, in order to include people with SCD in the labor market, such as through employment places.

This is one of the few studies examining the perceptions of people with SCD and leg ulcers about family relationships. In this sense, the results may contribute to raise new studies, besides favoring the debate on the scope of care and education measures about sickle cell disease, in order to include family members, strengthen the care network and avoid stigma in family interactions.

The reduced number of participants with SCD and leg ulcers, who performed dressings weekly in the reference center, can constitute a possible limitation of this study, not allowing generalizations. Furthermore, a larger sample could reveal other themes and aspects of family interaction. Nevertheless, the use of deep

face-to-face interviews and the analysis resources adopted allowed achieving the objectives and understanding the phenomenon explored.

Conclusion

This study showed that the sick attribute importance to family members to face the adversities promoted by the disease, as the care received contributes to maintaining a routine treatment, but also limits them to leisure activities with overprotection attitudes.

On the other hand, at the same time, they highlight that the family is a source of ill-treatment, upon not understanding the physical limitations imposed by the disease, which leads the sick to feel uncomfortable in the family environment and to feed feelings of uselessness, reinforced by the dependence on care and discrimination suffered.

This study contributes to the theoretical and practical field of nursing care, by offering elements that justify greater inclusion of the sick in the care itself, articulation of the support network to reduce the burden of care and health education extended to the family, with a view to minimizing the unawareness of the disease and its clinical manifestations, besides providing guidance for the prevention of psychological and social disabilities resulting from the disease and its chronicity.

Collaborations:

1 – conception, design, analysis and interpretation of data: Luana Santana Brito and Evanilda Souza de Santana Carvalho;

2 – writing of the article and relevant critical review of the intellectual content: Luana Santana Brito, Sheila Santa Bárbara Cerqueira and Luciano Marques dos Santos;

3 – final approval of the version to be published: Luana Santana Brito and Evanilda Souza de Santana Carvalho.

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