

# Being a man with sickle cell disease: discourses about falling ill and self-care

Ser homem com doença falciforme: discursos sobre adoecer e cuidar de si  
Ser hombre con anemia falciforme: discursos sobre enfermarse y cuidar de sí mismo

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## Abstract

**Objective:** To understand the experience of masculinity in the illness of men with sickle cell disease and the challenges for self-care.

**Methods:** This descriptive and qualitative study was developed in a reference center for monitoring people with sickle cell disease. Thirteen adult men with sickle cell disease participated, who responded to a drawing-story with a theme and a semi-structured interview. Data were analyzed by Collective Subject Discourse.

**Results:** The discourses of men with sickle cell disease were organized into four central ideas: *Finding oneself ill, knowing the disease and performing self-care; The limitations imposed by the disease permeate masculinities; Stigma and discrimination add to suffering caused by the disease; Men also feel pain and need to take care of themselves.*

**Conclusion:** The hegemonic masculinity model is contradicted by limitations of illness and by learning of self-care, promoting the resignification of being a man based on the experience of chronic disease.

## Resumo

**Objetivo:** Compreender a experiência da masculinidade no adoecimento de homens com doença falciforme e os desafios para cuidar de si.

**Métodos:** Estudo descritivo, qualitativo, desenvolvido em um Centro de Referência para acompanhamento das pessoas com doença falciforme. Participaram 13 homens adultos com doença falciforme, que responderam ao desenho-estória com tema e entrevista semiestruturada. Os dados foram submetidos à análise do Discurso do Sujeito Coletivo.

**Resultados:** Os discursos dos homens com doença falciforme foram organizados em quatro ideias centrais: *Descobrir-se enfermo, conhecer a doença e assumir o autocuidado; As limitações impostas pela doença perpassam as masculinidades; Estigma e discriminação crescem o sofrimento causado pela doença; Homem também sente dor e precisa cuidar de si.*

**Conclusão:** O modelo de masculinidade hegemônica é contrariado pelas limitações do adoecimento a pelo aprendizado do autocuidado, promovendo a resignificação do ser homem a partir da experiência da doença crônica.

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Conflicts of interest: nothing to declare.

## Resumen

**Objetivo:** Comprender la experiencia de la masculinidad en hombres enfermos con anemia falciforme y los desafíos para cuidar de sí mismo.

**Métodos:** Estudio descriptivo, cualitativo, llevado a cabo en un Centro de Referencia para seguimiento de las personas con anemia falciforme. Participaron 13 hombres adultos con anemia falciforme, que respondieron al dibujo-cuento con tema y entrevista semiestructurada. Los datos fueron sometidos al análisis del Discurso del Sujeto Colectivo.

**Resultados:** Los discursos de los hombres con anemia falciforme fueron organizados en cuatro ideas centrales: Descubrirse enfermo, conocer la enfermedad y asumir el autocuidado; Las limitaciones impuestas por la enfermedad atraviesan las masculinidades; El estigma y la discriminación aumentan el sufrimiento causado por la enfermedad; El hombre también siente dolor y necesita cuidarse a sí mismo.

**Conclusión:** El modelo de masculinidad hegemónica se ve desafiado por las limitaciones de la enfermedad y por el aprendizaje del autocuidado, lo que promueve la resignificación del ser hombre a partir de la experiencia de la enfermedad crónica.

## Introduction

Sickle cell disease is the most prevalent hereditary condition in the world. In Brazil, it affects about 0.3% to 0.5% of the black population.<sup>(1)</sup> It is characterized by chronic hemolytic anemia, vaso-occlusion and progressive vascular damage that affects multiple organ systems, bringing acute and chronic consequences, such as episodes of acute pain, chronic pain syndromes, acute chest syndrome, anemia, stroke and silent cerebral infarct, cognitive dysfunction and pulmonary hypertension, among others, causing intense physical and psychological distress to sick individuals.<sup>(2-4)</sup>

In Brazil, men with sickle cell disease live an average of 53.3 years, while women live 56.5 years.<sup>(3)</sup> Men, in general, have less compliance with treatment of chronic diseases, as therapeutic regimens require great effort from sick individuals to adopt lifestyle habits and maintain a strict discipline of care.

Sickle cell disease screening was included in the National Neonatal Screening Program in 2001, contributing to the institution of care from the first weeks of life. The purpose of this screening was to prevent and delay complications as well as to treat them early. People born before that date can access the diagnosis late and only from the expression of complications.<sup>(3,4)</sup>

Men's health care gained new direction from the Brazilian National Policy for Comprehensive Men's Health (*Política Nacional de Atenção Integral à Saúde do Homem*), established in 2009, by Ordinance 1,944 of the Ministry of Health.<sup>(5)</sup> With regard to men with sickle cell disease, the services offered to them need to follow the guidelines established by

the Brazilian National Policy for Comprehensive Care for People with Sickle Cell Disease (*Política Nacional de Atenção Integral às Pessoas com Doença Falciforme*), with a view to developing comprehensive care strategies, reducing complications and improving quality of life. Such political initiatives have based, in their guidelines, perspectives centered on the relational issues of sex and race, considering the influence of these markers on the social construction of masculinities and on the way in which health needs, vulnerabilities, illness and care practices.<sup>(6)</sup>

Considering that illness and care are social phenomena crossed by discourses, values and norms attributed to sex, this research sought to answer the question: How do men experience the experience of being a man, falling ill and taking care of themselves in sickle cell disease?

The aim of this study was to understand the experience of masculinity in the illness of men with sickle cell disease and the challenges for self-care.

## Methods

This descriptive and qualitative study was developed in a reference center for people with sickle cell disease in Bahia State, northeastern Brazil. This research is part of another project, entitled Production of Care and Social Technologies for Men's Health Care and Education in the Municipality of Salvador, Bahia, Brazil, and was approved by Institutional Review Board, under Opinion 3,313,517. To achieve the required rigor and quality, it met the 32 verification items of the Consolidated Criteria for Reporting Qualitative Research (COREQ) relating to the research team, the research project and data analysis.<sup>(7)</sup>

Eighteen men aged 18 years or older and diagnosed with sickle cell disease were invited. Of these, five were excluded for complaining of pain at the time of the meeting, resulting in a total of 13 self-reported black participants aged between 18 and 60 years, with low education and average family income of one wage.

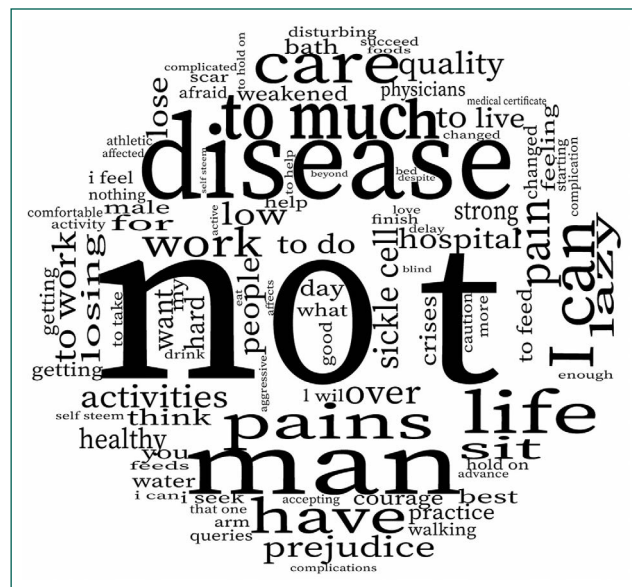
Approaching participants took place in the waiting room, in the nursing office. Data collection took place between March and June 2018, in a private room, with the presence only of a male interviewer and interviewee. The decision to conduct the interview by a man is justified by the fact that the participants themselves indicated, in conversations with the research group, that they felt more comfortable talking about their experiences of illness with another man, mainly due to related issues to intimacy, sexuality and the experiences of priapism. The men responded to drawing-stories with a theme and semi-structured interviews. The discourses and stories obtained by both techniques were recorded and later transcribed in full by the first author.<sup>(7)</sup>

Data were processed in the NVivo<sup>®</sup> software, which allowed extraction in the word cloud and discourse clippings, which were analyzed using the Discourse of the Collective Subject method, which unveiled the key expressions, the central ideas and the anchorages, for the formulation of synthesis-discourses.<sup>(8)</sup> The central ideas were validated by a research team, composed of three undergraduate students in Scientific Initiation training, one PhD student and two PhD holders.<sup>(7)</sup> Interpretation of results was based on the masculinity framework.<sup>(9)</sup>

## Results

The experiences of masculinities in the illness of men with sickle cell disease, unveiled in the categories described below, are supported by a word cloud (Figure 1).

The words express the essence of the study's central ideas. Consequently, among the most frequent and the most expressive are experiences of daily routines generated by sickle cell disease in men's lives ("pain", "hospital" and "consultations"), which re-



**Figure 1.** Word cloud about the experiences of masculinity and illness of men with sickle cell disease

veal the presence of impacts ("prejudice") and limitations ("altered", "changed", "I cannot", "I am not capable" and "I am no longer the man I used to be"), also affecting their masculinity.

The four central ideas learned from the empirical material are presented and described below.

### Central idea A: Finding oneself ill, knowing the disease and performing self-care

Men's discourse about the experiences of obtaining the disease diagnosis describes the trajectory of consultations and exams, the symptoms that evidenced the emergence of complications, the emphasis given to difficulties as consequences of sickle cell disease, interactions with health professionals, therapeutic measures and the adoption of new care practices.

"As soon as I discovered sickle cell disease, it was that scare, I thought I would become weaker, that I couldn't do or eat anything. I started taking care of my health. I visited physicians, started doing exams, eating at the right time, eating fruit and vegetables, stopping drinking soda and foods that were bad such as salt, fat and alcohol. After discovering this disease, it changed a lot, mainly because I couldn't stand the muscle aches and painful crises all over the body, making me need to take a lot of strong medications and constantly having to go in search of a physiotherapist. Also, I lost some of the movement

I had before in one of my arms and I also suffer from priapism. As the disease progresses, I can no longer run, get in contact with cold water and exert physical effort. I have to be very careful not to hurt myself, due to the healing problems I experience. To avoid these problems, I try to wear comfortable shoes so that I can practice physical activities such as walking, muscle-building, and soccer. In order to carry out these activities, I drink a lot of water in order to recover and I also search for information on the internet, on Google, as a way to improve my quality of life.”(DCS of men experiencing sickle cell disease).

### **Central idea B: The limitations imposed by the disease permeate masculinity**

Men emphasize the male ideal based on strength and virility, which they would like to achieve, in addition to low expectations of putting into practice their personal fulfillment plans, such as building a professional occupation and rising in the world of work. Difficulties perceived in the exercise of sexual activity with their partners were recalled, ranging from pain throughout the body, which discourages them from taking the initiative for sex, to sexual dysfunction, as a consequence of priapism.

“I’m never 100% healthy as it’s a disease that needs a lot of care. At the same time that I’m fine, I’m feeling pain, and this makes me very weak, living daily with some complication. If I could stand it, I would go to work with a formal contract, but unfortunately, I can’t, because I’m in pain, I can’t miss the night and spend time to eat. Nowadays, I no longer have that vigor and strength to perform certain services that are offered in the job market, such as those who have heavy activities and, as a man, this affects me. Lately, I’ve been self-employed to support myself, but what I really wanted was to work to have my active life again. To study, I have difficulty, because my thinking is slower for reading and writing. I can’t work out using physical strength and, with that, I can’t have that defined and athletic body that I would like and that affects my self-esteem. I become more dependent on the hospital, more restricted, and all this has changed my future. It also affected my sex life, because I often

end up not being able to practice due to the pain. Sometimes it is necessary to interrupt the relationship and only come back after the pain subsides. I end up losing my will, I have no pleasure, and because of that, I can’t relate to a normal person. This ends the man’s masculinity and also affects my willingness to live.”(DCS of men experiencing sickle cell disease).

### **Central idea C: Men also feel pain and need to take care of themselves**

Men remember the labels given to them by those who do not know or do not understand the disease, the implications of this lack of knowledge for opportunities to access and remain in the labor market, as well as the difficulties in physically attending to work for those who do not achieved school performance and qualify for jobs considered less “heavy”. Discrimination makes men perceive the uncertainty about their future, and the risk of exclusion leads them to work even in pain.

“Sometimes I want to do activities and I can’t, and I hear from other people that I’m lazy. Many of these people don’t know the pain I feel. The moment I had ischemia, I was depressed, afraid of going blind, because I slept well and when I woke up, I lost my sight in both eyes. In times of pain, I get very low, I often think about giving up, because the pain is very strong. A disease like this is like a delay in life, which brings you down. It is an aggressive disease that generates crises, taking me to the hospital a lot, disrupting my daily life. Because of this disease, there is a lot of prejudice, and if the person does not have help, they get depressed. I have had to go to work several times in pain, not being able to talk to the boss, for fear of being fired, because my boss does not understand my health problem, my need to constantly go to the hospital to take medication, he does not accept the medical certificates and deducts the absence of the day not worked from my wage.”(DCS of men experiencing sickle cell disease).

### **Central idea D: Men also feel pain and need to take care of themselves**

The discourses point out the male chauvinism present in men’s perceptions about care and reveal that

the experience of illness leads them to develop a more positive narrative towards self-care, basing their search on hope for the extension of life with quality. Thus, men describe the routine of care to adapt to the adversities promoted by the disease and reinforce the need for health promotion care, to prevent or delay complications.

“In fact, men focus more on work. They are more concerned about expenses, other things, and they end up neglecting. Relax, because they know that if they take a break, they will be wasting time and money. There is also a self-prejudice, because men don't have the courage to open up, they don't have the courage to speak the truth, because they themselves have the prejudice and think that men don't feel pain, because they are male. When you find a man who takes care of himself, there is discrimination in society that sees this issue as taboo. They immediately think that man is fresh, soft, but I think that if I take care of myself I will live longer and not lose the best part of life, which is to reach old age. Men have to take care of themselves, they need to look for the health service out of obligation and not only when they feel pain, they need to go often, seek routine examinations, especially when they reach old age, to have a better quality of life. Although many people have prejudice that men are male and do not feel pain, I think that everyone has to take care of themselves, because care is not just for those who feel pain, but for those who love themselves and want a long life, and as I have sickle cell disease, if I don't take care of myself, I'll get even worse. I want to see my children and grandchildren grow up, have a healthy life without complications, preventing me from being in a bed or depending on someone else.” (DCS of men experiencing sickle cell disease).

## Discussion

Censorship when talking about priapism and sexual dysfunction stands out as the study limitation, which may have been due to the fact that the interviews were conducted at the healthcare center itself. There was also the fact that participants are

exclusive dependents of the Unified Health System (*Sistema Único de Saúde*) and belong to the same social strata, which may have restricted common experiences to the same social class. To overcome such limitations, we recommend the expansion of studies to other care settings to reach men from different social classes.

Although it is a hereditary disease, a situation that would result in learning about the disease and the necessary care to preserve health from childhood, the study participants had a late diagnosis, implying changes in the previous standard of care. It is also worth noting that this experience is marked by the pain that progressively incapacitates men to lead their lives as society expects them as sexual beings, workers, active, independent and capable of producing resources for their own sustenance and maintenance of their family group.

Thus, when they realize that their plans are frustrated by the disease, men perceive the disease as destructive, but they reframe it and understand it as a lesson on taking care of themselves. This new meaning implies a change in behavior and the development of care practices, which are mediated by the presence of healthcare professionals and by the support of digital resource, made possible by the internet.

As the changes resulting from sickle cell disease emerged, practices adopted by men are aimed at minimizing the occurrence of new events and complications and, consequently, of the limiting factors generated by the disease. Such changes are permeated by the imagination of reaching a satisfactory status of quality of life.

Intertwined with these transformations, attributes of hegemonic masculinity, such as strength, virility and invulnerability, incite in men exposure to risks, the practice of unhealthy habits, such as alcoholism and smoking, contempt and devaluation of self-care, causing resistance to seeking healthcare services.<sup>(9-11)</sup>

Involved in an ideal of hegemonic masculinity, which represents a model of social construction of the centralizing male, still dominant, and that imprints normative expectations on men related to masculinity, demands that they be physically

tough and fearless in the face of risks or dangers.<sup>(9)</sup> Men trained to meet these benchmarks have uncontrolled diseases, adhere with difficulty to new dietary changes and the continuous use of medications, and are reluctant to seek help and discuss their health.<sup>(12)</sup> However, pain and chronic illness reconfigure the male's place in the care universe, changing social, affective/relational and physical positions, giving rise to sensitivity, motivation and acceptance of disease and treatment.<sup>(10,11)</sup>

In this study, men highlighted everything that the disease prevents them from doing and how these obstacles affect the models of masculinity that influence them, from the presentation of their bodies to the way they behave in intimacy. There is an emphasis on painful experiences and that of priapism, which affect the dimensions of life of sick individuals, both surprising them unexpectedly and interrupting their daily activities, as well as persisting in a chronic and tiring way, depleting their energy to engage in interactions.<sup>(13)</sup>

When faced with the expressive threat of compromising the ideal of masculinity by complications, whether the ability to work, provision for their home and pain tolerance, men express concern with health care and report the difficulty to freely exercise self-care, considering the non-legitimacy of their peers and society, which still does not recognize men as a subject in need of care.<sup>(9)</sup>

Hormonal changes resulting from the disease or treatment with hydroxyurea imply a reduction in sexual performance, frustrating sexual and reproductive expectations, and may compromise the attribute of male virility.<sup>(14,15)</sup> A study revealed that concerns about the possibility of failing in the sexual encounter, the fear of having a child with disease and the difficulty of keeping a job affect the exercise of sexuality and prevent carrying out paternity projects.<sup>(16)</sup> Furthermore, priapism is perceived as a deficit in genital health, a decline in sexual function and a cause of embarrassment in emergency units and in intimate interactions.<sup>(17)</sup>

Considering these experiences closely linked to the ideal of masculinization, uncertainties about the future in the face of chronic illness are intensified, as participants feel distanced or excluded

from the world of work, hindering their permanence and social ascension and resulting in feelings of less valued by themselves. This is because the moral and social values of work would ensure them both autonomy, independence and personal fulfillment as well as the achievement of identity and social status as a worker.<sup>(18,19)</sup>

Since they suffer from social impacts, for not achieving formal education, people with sickle cell disease need to dedicate themselves to more physically demanding jobs. However, they may be unable to work or keep a steady job, having health problems and frequent pain crises. These factors affect the ability to obtain consistent preventive care, making self-care even more important.<sup>(20)</sup>

Added to these impacts and as a result of constant pain, depression in people with sickle cell disease is higher than in the general population. However, depression in sickle cell disease also results from the suffering caused by discriminatory attitudes of people who reduce the sick to stereotypes, allocating uncourteous and unequal treatment to them, especially in emergency units, attributing more suffering to them than the disease itself and discouraging them to seek help, when necessary, due to anticipation of stigma.<sup>(21,22)</sup>

Having their mental health situation compromised and intensified by the stigmatization process, the suffering generated by a chronic disease leads men to a strict routine of care that reminds them of the need to be vigilant about their bodies and their health. In this regard, men perceive that they contradict the hegemonic models of masculinity still in force in the current Brazilian context, as attitudes of care are opposed to the idealized image of an "invulnerable" man.

The excruciating pains of sickle cell disease place the person on his or her own fragility and announce complications that can lead to death. Vulnerability perception is positive, as it reinforces, in the individual, the need to comply with self-care measures; on the other hand, it can increase psychological distress when they are faced with material resources and a support network for self-care. Being closer to support networks allows people living with sickle cell disease to expand the planning of interventions

of a psychosocial nature, in an effective way and capable of promoting quality of life.<sup>(23)</sup>

As support for coping with multiple impacts, support networks can be weakened due to the process of self-isolation and social isolation caused by illness. Men with sickle cell disease need to be encouraged to participate in associations and help groups that favor positive interactions, learning and building bonds.<sup>(24)</sup>

## Conclusion

This study allowed us to understand that men with sickle cell disease recognize themselves as beings forged by social expectations of sex, with limitations imposed by a disease that calls into question the values of hegemonic masculinities, making them reflect on the pressures of machismo and their place as the subject of care, with an appreciation of self-care. The findings provide substantial implications for care practice in nursing and health, making the analysis of daily life, the impacts generated by the disease and the social marker of masculinities as essential components for the clinic more evident. The study also indicates a deepening of the coping strategies adopted by men in the face of the impacts of sickle cell disease and prompts the development of targeted actions to minimize them.

## Collaborations

Sousa AR, Jesus AC, Andrade RCS, Lopes TFA, Jenerette CM, Carvalho ESS and Pereira A declare that they contributed to the study design, data analysis and interpretation, article writing, relevant critical review of intellectual content and approval of the final version to be published.

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