

# Experiences of illness among individuals with sickle cell anemia and self-care strategies

Experiências do adoecimento de pessoas com anemia falciforme e estratégias de autocuidado

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## Keywords

Self care; Anemia, sickle cell; Qualitative research; Sick role; Quality of life

## Descritores

Autocuidado; Anemia falciforme; Pesquisa qualitativa; Papel do doente; Qualidade de vida

## Submitted

August 18, 2014

## Accepted

August 26, 2014

## Abstract

**Objective:** To determine the experience of sick individuals with sickle cell anemia and their self-care strategies.

**Methods:** This was a qualitative study of 17 individuals with sickle cell anemia. Data collection and analysis occurred simultaneously by open codification and categorization, according to steps in the theory based on data. This procedure led to the development of categories related to the experience of individuals who have sickle cell anemia and their self-care.

**Results:** Experiences of patients who became chronically ill enabled the construction of strategies to better determine the disease, changes in daily life, and the manner in which it affects how patients observe and experience time. Also identified were specific skills for self-care that were developed from lessons learned and mistakes made.

**Conclusion:** We found that individuals with sickle cell anemia had several favorable approaches for adapting to having become sick during adulthood.

## Resumo

**Objetivo:** Conhecer as experiências do adoecimento de pessoas com anemia falciforme e suas estratégias para o autocuidado.

**Métodos:** Pesquisa qualitativa realizada com 17 pessoas com anemia falciforme. A coleta e a análise dos dados ocorreram simultaneamente, realizando-se a codificação aberta e sua categorização, segundo os passos da Teoria Fundamentada nos Dados. Tal procedimento deu origem a categorias relativas à experiência do adoecimento de pessoas com anemia falciforme e autocuidado.

**Resultados:** As experiências com o adoecimento crônico possibilitaram a construção de estratégias para conhecer melhor a doença, determinaram mudanças na vida cotidiana, e afetaram o modo como cada pessoa observa e vivencia o tempo e como as habilidades específicas para o autocuidado foram desenvolvidas a partir dos aprendizados e deslizes cometidos.

**Conclusão:** Constatou-se que as pessoas com anemia falciforme apresentaram vários elementos favoráveis em busca de adaptação ao adoecimento na fase adulta.

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## DOI

<http://dx.doi.org/10.1590/1982-0194201400082>

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**Conflicts of interest:** none reported.

## Introduction

The World Health Organization (WHO) recognizes sickle cell anemia as a priority for public health, especially because of problems with access to health services in several regions of the world. In Brazil, this disease is predominantly found among black people, pardos, and Afro-descendants. In general, 3,500 children/year are born with sickle cell anemia, and 1 child in a 1000 births has the disease. The Bahia state, northeast Brazil, has the highest incidence of sickle cell anemia: 1 case for every 650 newborns and 1 individual with sickle cell trait for every 17 births.<sup>(1)</sup>

Sickle cell anemia has been treated as a single medical specialization for long time, mainly in hematology, and has not been a part of other health services. Care for sickle cell anemia patients must become a focus of primary care services.

Publication of a self-care manual for individuals with sickle cell anemia revealed the need to share with all health professionals self-care practices, such as meetings among individuals (i.e., a collective construction). These practices can be changed from a disease-centered model to one that prioritizes the daily practices of individuals and families who seek health care.

To understand individuals with sickle cell anemia, experience is important to organize nursing care and obtain broader access to care for this population group. This study aimed to understand the experience of sick individuals with sickle cell anemia and self-care strategies.

## Methods

This descriptive study with qualitative analysis used a theory based on data as the methodological reference point. This approach enabled us to develop a theory from the data obtained to perform concomitant and comparative analysis of the data.<sup>(2)</sup>

This study was developed in three municipalities of Bahia state. We included 17 patients aged 18 to 49 years old who were diagnosed with sickle cell anemia.

Participation selection was intentional and theoretical. After a search for participants conducted with community health agents, we invited individuals to participate; these initial participants then referred others to participate. We attempted to obtain a varied sample in relation to age, time of diagnosis, formal education and sex.

Data were collected by “deep interviews”.<sup>(3)</sup> In the first meeting, we requested participants to reveal their experience with sickle cell anemia. Interviews were transcribed and simultaneously analyzed. This process yielded data that we used to develop a script for further interviews. The findings from the interviews were analyzed and codified according to inductive development of qualitative research, but without losing the characteristics of an open interview.

Interviews occurred at participants’ houses. Participants’ testimonials were digitally recorded and later transcribed in full. As mentioned earlier, data collection and analysis occurred simultaneously through open codification and categorization based on steps of theory grounded in data.<sup>(2)</sup> During open codification, data were analyzed line by line, examined, and compared for similarities and differences. Through this process, the phenomena were questioned and explored, which enabled discoveries.

Codified data were grouped by similarities. Each category was considered saturated when it was not possible to add any more new data. This procedure led to the creation of categories for the experiences of sick individuals with sickle cell anemia and self-care.

To maintain rigor in the study, we used the following strategies: all interviews, after transcription, were made available to all participants in order to verify that interviews were represented in a manner consistent with how the data were being analyzed, and we used consolidated criteria for reporting qualitative research (COREQ) as the supporting tool. This tool for qualitative research methods is composed of 32 items that should be verified by the research team for the research project and data analysis.<sup>(4)</sup>

Development of this study followed national and international ethical standards for research on human subjects.

## Results

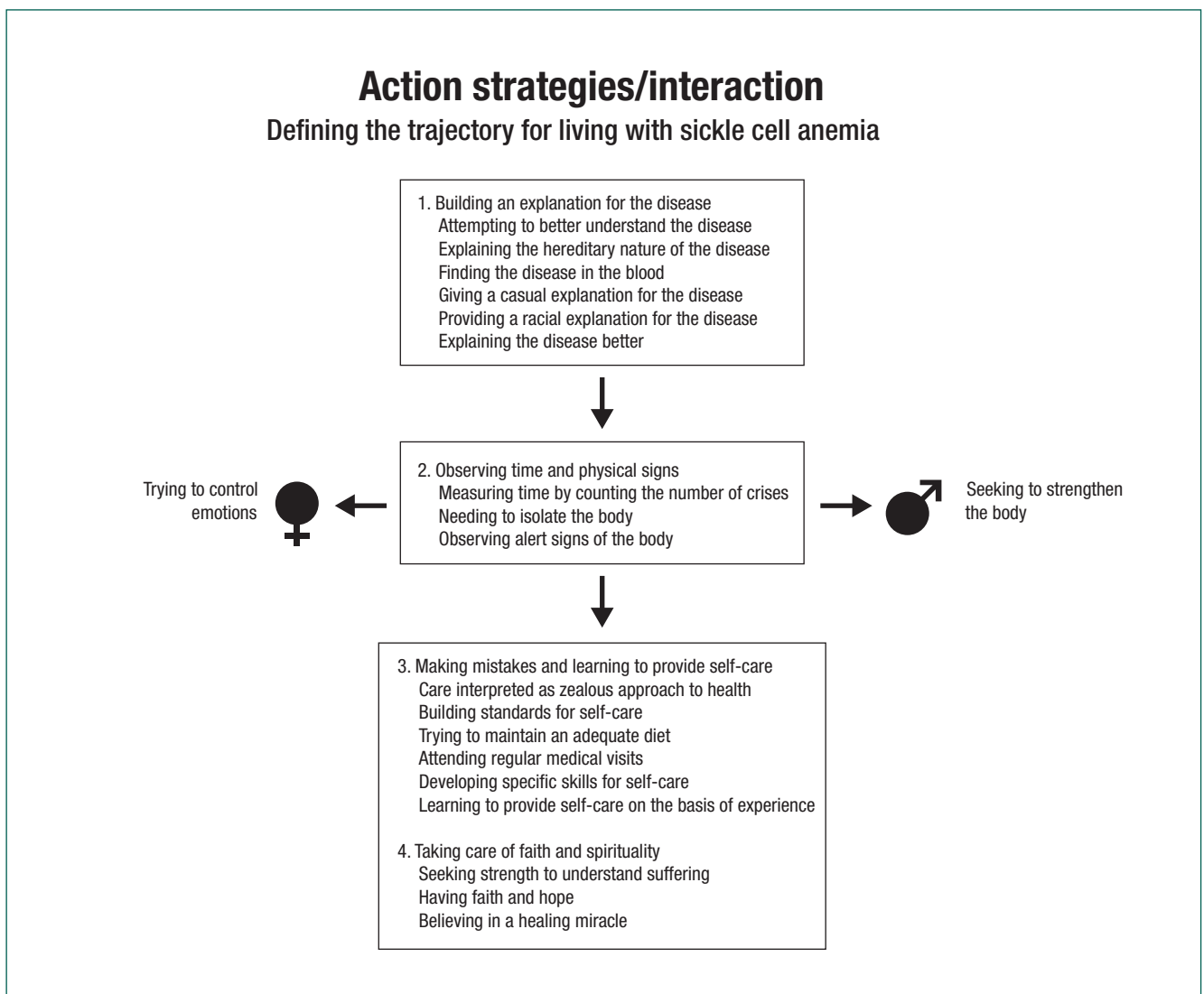
According to the referral adopted, the resources that the patients created to manage the process of becoming sick, as well as self-care strategies, were represented by four categories, as shown in figure 1.

The category “building an explanation for the disease” concerns the efforts of patients to better understand sickle cell anemia. This is an important process that involves day-to-day organization, taking care of themselves, and facing the reality of their situation. In collecting the experiences of the participants, we identified the rupture caused by the disease and the need to reclaim balance in order to proceed forward.

The category “observing time and physical signs” shows that being sick results in changes to daily life and affects the way in which each person observes and experiences time.

The category “falling and learning to provide self-care” identifies that steps followed to keep the disease stabilized, such as self-care, are meaningful. In this sense, self-care means a zealous approach to health behavior and the need to be alert to physical signs and symptoms.

Finally, the category “taking care of faith and spirituality” shows that in critical moments, strategies are employed to ensure that the experience of becoming sick as incorporated into the daily routine will be valid. The study participants seek strength



**Figure 1.** Flow diagram about living with sickle cell anemia

in facing suffering to help them overcome difficult moments.

## Discussion

The study is limited because qualitative research does not enable generalization of results. However, our findings can contribute to the knowledge of demands placed on individuals with sickle cell anemia for self-care.

The category “building an explanation for the disease” shows that sickle cell anemia has complex meanings beyond a simply biological dimension. Its social meanings incorporate values and structure of elements related to health professionals,<sup>(5)</sup> who are always reinterpreting the biomedical model and looking for common-sense knowledge.

When individuals acquire information, they begin to construct an explicative frame that includes biological, behavioral and racial factors and that shows the idea of integrative plurality to explain the presence of the disease. This frame of meaning is built into the interactions with several environments and the individuals who make up their social relationships; these interactions are also changed by these relations and the course of the disease.<sup>(1)</sup>

Explanations are plentiful and differentiated according to whether they are created as important referral points in the interface of the individual with society. This is equally important in helping to understand several aspects of life, to realign the present, and plan actions for the future. In the studied group, we identified their effort to present a biomedical, legitimated and hegemonic discourse related with health and disease, which necessarily does not implicate, in complete understand of this knowledge.

To pursue an explanation about the disease helps to answer more safely, be more open, and be available to face challenges. Efforts to strengthen patients' comprehension and learning during daily life can help them build their knowledge of and ability to manage self-care.

We observed that the type of disease determined the patients' way of life and how they interpret time,

defined mainly by crises. To be sick, therefore, is not a constant, but there is a determined period that depends on remission phases and exacerbation of the disease.<sup>(6)</sup> In this sense, years and months are considered good or poor, based on crises that appear.

In this interaction with time, we also observed a relationship with climate because crises occur more often in cold periods. The winter is seen as threatening the patients' lives because symptoms and crises become more latent. Individuals with sickle cell anemia, in general during these periods or at night, need to isolate their body as a self-care strategy to protect and avoid the precipitation of crisis.

Following this observation of time, we identified alert signs of how the body responds to being sick (the circumstances that cause and can bring challenges related to indisposition and fatigue). Weakness and indisposition to conduct daily activities are among these signs.

The chronicity of a disease is characterized by uncertainty regarding the future. Although individuals have periods of stability, they need to be alert and take self-care measures, such as adopting changes in their eating habits. Some patients experience tiredness, weakness, and pain every day, and others have moments in which these signs are present and times of “normality”.

Signs of an impending crisis vary from person to person, but they are all aspects and changes perceived in the body. Dehydration signs indicate that the body needs water.<sup>(1)</sup> Some reports indicate that crises can begin spontaneously, with little warning. Thus, the patient wages a daily battle to maintain daily life activities with continuous care, and sometimes there is a need to intervene so that the body remains strong.

We found that men reported using vitamins and seeking ways to strengthen the body and avoid fatigue; women tried to control their emotions because those also trigger crisis (generally with regard to physical aspects and stressful situations at home).<sup>(1)</sup> It is possible to identify how difficult it is for men to say that they are sick by their immediate correction of the term “more or less sick” because they do not feel totally incapable of conducting daily activities.<sup>(7)</sup>

Because patients cannot control when crises will appear, they are aware of the need for daily control to avoid future complications. In this sense, they live with a disease that can be controlled by self-care and cannot neglect themselves.

Building norms for self-care consists of a series of norms that are instituted. The evolution of chronic condition is marked by a routine of time, food that can be ingested or not ingested, medicines that can be taken, exams to be conducted periodically, and control of hemoglobin. There are rules to take care of the body, protect from the sun and cold, and eat a healthy diet. Sometimes slippage occurs because of a hurried life or the difficulty young people have in taking care of themselves.<sup>(5)</sup>

To visit the doctor consistently is also important for care, such as the performance of exams. Regular follow-up with specialists is necessary. The aggregated knowledge gathered by observing the recurrence of fundamental experiences helps construct the meaning of care and create rules for facing daily life with a chronic disease. Elements of care must provide support and help patients pursue their daily life activities. The meaning of care is developed by incorporating knowledge of different origins and orders that are molded by physical experience.

Self-care strategies that are developed with experience are based on daily practice and allow patients to keep their lives as close to normal as possible. Strategies for facing chronic illness often transcend mere bodily care—it is also necessary to attend to faith and spirituality.

To accept the restrictions, health implications, and life changes that accompany sickle cell anemia is difficult, and to do so when supported only by fundamental materials is not be enough. Religiosity/spirituality is a predictive factor for well-being and social support. Seeking support from religious practice is one of the ways patients face health problems. In our study, religiosity and spirituality appeared as elements of care directed to health and the experience of illness. Going to church, praying or listening to religious music seem to be strategies that help the individual to feel healthier and, sometimes, improve pain, in addition of providing a space of refuge and social support.<sup>(8,9)</sup>

To believe that life is guided by a superior force can help patients find meaning in life with a chronic disease. According to this view, physicians cannot always provide healing; healing is present in hope and depends on the divine will. To believe in healing is also a form of obtaining relief, perhaps even interpreted as a miracle and not associated with associated with medical knowledge and becoming possible, because it is transferred for divine field: faith in God<sup>(8,9)</sup> Going forward depends on, above all, integrating all the patients' feelings with expectations and support that will be organized on a pathway to overcome the suffering caused by sickness.

## Conclusion

Experience of sick individuals with sickle cell anemia and self-care strategies indicated favorable elements in seeking for adaptation to the sick in adult phase.

## Collaborations

Cordeiro RC; Ferreira SL and Santos ACC contributed to the conception of the Project, analysis and interpretation of data, drafting the manuscript, critical review relevant for intellectual content and approval of final version to be published.

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