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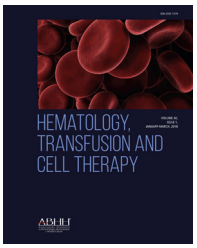

Original article

Barriers experienced in self-care practice by young people with sickle cell disease

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ABSTRACT

Objective: To identify barriers to the self-care practice of young people with sickle cell disease.
Method: This qualitative study was conducted with 17 individuals with sickle cell disease aged between 13 and 24 years in Belo Horizonte, MG, Brazil in March and April 2017. An interview investigated the barriers to self-care practice and the feelings associated with sickle cell disease. Data were transcribed and analyzed according to Bardin's perspective using the following steps: (1) pre-analysis, (2) exploration of the material, and (3) treatment of the results (inference and interpretation).
Results: Five thematic categories emerged: (1) feelings: anger, sadness, and fear; (2) bullying and stigmatization: challenges regarding walking, speaking, or behaving, as well as patient labels; (3) cognitive factors: doubts related to medication, hydration, heredity and maternity; (4) medication compliance: fear of the side effects suffered and anger triggered by the obligation to use the medication; (5) family issues: complaints of not earning the mothers' trust to live independently.
Conclusion: The barriers to self-care in young people with sickle cell disease indicate difficulties related to emotional, behavioral, and environmental aspects. Understanding these factors will favor a better adaptation of youths to the context of sickle cell disease.

Introduction

The transition period between childhood and adulthood, called adolescence, represents a challenge in the management of different chronic conditions. This problem is even harder for young people with sickle cell disease as it requires complex care. The need of learning to take care of oneself with autonomy, to be responsible for health choices, and to adapt to illness are some of the difficulties faced by the youths.[1]

To take care of yourself, referred to as self-care, comprises a process in which young people with sickle cell disease perform activities to improve their health and well-being, requiring attitudes compatible with medical guidelines associated with efforts to minimize disease-related complications. These actions include, among other things, the correct use of

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medication, hydration, and care about extreme temperatures and of high impact activities.[2,3]

Nevertheless, adherence to self-care practices might be permeated by barriers that demand an understanding of their multifactorial aspects and the characteristics to which they may be associated.[4] The literature indicates that barriers pervade the behavioral, sociocultural, and psychosocial domains. As an example, cultural beliefs about disease, socioeconomic status, presence or absence of social support, and past negative experiences with medical teams play key roles in adherence to self-care.[5,6]

Seeking to identify and understand the barriers experienced by young people with sickle cell disease is essential to plan and systematize better health care practices to improve adherence to self-care and promote the well-being of this population.

Objective

In this perspective, this study aimed to identify barriers to self-care practice in young people with sickle cell disease.

Method

This is a descriptive and exploratory qualitative study conducted with 17 young people with sickle cell disease treated in the Outpatient's Clinic of the Fundação Centro de Hematologia e Hemoterapia do Estado de Minas Gerais in Belo Horizonte (Hemominas), MG, Brazil, part of the Centro de Educação e Apoio para Hemoglobinopatias de Minas Gerais (CEHMOB) during March and April 2017.

The inclusion criteria were individuals aged between 13 and 24 years diagnosed with sickle cell disease [hemoglobin (Hb) SS, Hb SC, and Hb Sβ-Thalassemia] and able to understand and answer questions. Data collection occurred through semi-structured face-to-face interviews conducted in a reserved room at the Hemocentro, without noise and adequate for dialog. The research reached the saturation criteria proposed for qualitative research by the 17th interview. All individuals accepted to participate in the research.

Each interview, carried out by the authors of this article, lasted for an average of 20 min. The interviews were recorded after the participants' consent and guided by the following questions: (a) for you, what is it like living with sickle cell disease? (b) tell me about the difficulties you face to take care of yourself and your health and (c) how do you feel about having to take care of yourself and your health? The questions were read in colloquial Portuguese, familiar to the context of each subject. All interviews were later transcribed using the ELAN software.

The contents of the interviews were organized after the complete transcription of the recordings, preserving their originality. For data analysis, these dialogs were systematized and categorized to compose a database considering recurrent opinions, dissent and consensus about the barriers related to self-care. Later, data processing and interpretation took place based on the content analysis technique proposed by Bardin that consisted in the following stages: (1) pre-analysis, partially guided reading of the material so that the researcher could become familiar with the expressed content, (2) exploration of the material, requiring several readings and reinterpretations, during which the material was organized so that the initial ideas were systematized and (3) treatment of the results, where all the material was separated into record units regarding each topic and category (inference and interpretation). It is also important to clarify that, to guarantee the anonymity of participants, the statements were codified by letters (I) and numbers (1–17). Reading and interpretation of the content identified five thematic categories: feelings, bullying and stigmatization, cognitive factors, medication compliance, and family issues.

To describe the profile of participants according to sociodemographic variables, a structured questionnaire containing information about age, gender, place of origin, racial background, education, and type of sickle cell disease was applied.

The study respected the formal requirements established in the national and international norms regulating research involving human beings and every research participant signed the free and informed consent form after it was approved by the Research Ethics Committees of the Universidade Federal de Minas Gerais (UFMG) and Hemominas (# 58078316.0.0000.5149).

Results

The sample consisted of 17 people with a diagnosis of sickle cell disease with a mean age of 17.8 years. Regarding gender, 47.1% were male and 52.9% were female. More than one-third (35.2%) had incomplete basic education, 52.9% had incomplete high school education, and 11.7% had quit school. About the origin, 52.9% were from Belo Horizonte and the metropolitan region and 47.1% from surrounding towns. As for the racial background, 64.7% declared themselves Black and 35.2% mixed (Black and White). The monthly family income of 11.7% of the cases was less than one minimum wage, another 11.7% of the families received between one and three minimum wages, 5.8% between three and five minimum wages, and the rest did not know or chose not to disclose the family income. Regarding the hemoglobin type of sickle cell disease, 41.17% had Hb SC, 29.4% had Hb SS, 5.8% had Hb Sβ-Thalassemia, and the others were unable to inform the type.

Categorical analysis identified barriers faced by young people with sickle cell disease in respect to self-care or even to attempting to look after themselves. Based on the analyzed reports, it was possible to group and classify the barriers in five thematic categories.

Feelings

Given the chronicity of sickle cell disease, emotional reactions related to barriers to self-care were identified with special reference to the feelings of anger, sadness and fear.

Anger was mentioned by most of the youths and was associated with the presence of pain, because, if it were not for the disease, there would be no such symptom or any other complication. It was observed that some participants who reported anger due to the sickle cell disease presented resistance to

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