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SELF-CARE PRACTICE IN PEOPLE WITH SICKLE CELL ANEMIA

Prática do autocuidado em pessoas com anemia falciforme

Práctica del autocuidado en personas con anemia falciforme

Natália Bastos Ferreira Tavares
Regional University of Cariri (*Universidade Regional do Cariri - URCA*) - Iguatu (CE) - Brazil

Nayara Monique Araújo do Nascimento
Regional University of Cariri (*Universidade Regional do Cariri - URCA*) - Iguatu (CE) - Brazil

Raimundo Tavares de Luna Neto
Regional University of Cariri (*Universidade Regional do Cariri - URCA*) - Iguatu (CE) - Brazil

Jucier Gonçalves Junior
Federal University of Cariri (*Universidade Federal do Cariri - UFCA*) - Barbalha (CE) - Brazil

Denise Maria Christofolini
ABC Medicine School (*Faculdade de Medicina do ABC - FMABC*) - Santo André (SP) - Brasil

ABSTRACT

Objective: To identify the application of Orem's self-care theory in patients with sickle cell anemia (SCA) at a regional hematology center. **Methods:** It is a study of a descriptive nature, with an exploratory and qualitative approach, held at the regional hematology center of an inland municipality of Ceará, Brazil, with patients diagnosed and treated for SCA. The data collection was carried out in May 2014, through an interview applied to patients with sickle cell anemia or their respective legal guardians, conducted while they were in the waiting room for medical care in the institution. The following guiding question was asked: "What are the main precautions you take to prevent the complications of sickle cell disease?". Data were analyzed according to Bardin's content analysis technique. **Results:** It was evidenced that patients lack an accurate knowledge about their disease, thus disadvantaging the primary foundation for self-care. The discovery of the disease usually occurs due to the need for clinical interventions in repeated episodes of pain. The painful events represent the main difficulties and causes of hospitalizations with the search for emergency medical services. **Conclusion:** The educational actions provided by the multidisciplinary health team make it possible for the SCA patient and caregiver to provide better care by means of self-care activities and actions.

Descriptors: Self-Care; Anemia, Sickle Cell; Nursing.

RESUMO

Objetivo: *Identificar a aplicação da teoria do autocuidado de Orem em pacientes portadores de anemia falciforme (AF) em um hemocentro regional.* ***Métodos:*** *Trata-se de estudo de natureza descritiva, com caráter exploratório e abordagem qualitativa, realizado no hemocentro regional de um município do interior do Ceará, Brasil, com os pacientes diagnosticados e em tratamento para AF. A coleta de dados se deu em 2014, sendo utilizada entrevista aplicada na sala de espera para atendimento médico na própria instituição. Os dados foram analisados conforme técnica de análise de conteúdo de Bardin.* ***Resultados:*** *Evidenciou-se que o paciente não apresenta um saber apurado sobre a sua patologia, desfavorecendo, portanto, as bases primárias para o autocuidado. A descoberta da doença geralmente se dá pela necessidade de intervenções clínicas em episódios repetidos de dor. Os eventos dolorosos representam as principais dificuldades e causas de internação hospitalar com a busca pelos serviços de pronto atendimento médico.* ***Conclusão:*** *As ações educativas fornecidas pela equipe de saúde multidisciplinar possibilitam ao paciente e cuidador de AF condições para uma melhor assistência por meio das atividades e ações de autocuidado.*

Descritores: *Autocuidado; Anemia Falciforme; Enfermagem.*

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RESUMEN

Objetivo: *Identificar la aplicación de la Teoría del Auto Cuidado de Orem en pacientes con anemia falciforme (AF) de un centro regional de hematología.* ***Métodos:*** *Estudio descriptivo de abordaje cualitativo y exploratorio en el centro regional de hematología de un pueblo del municipio de Ceará, Brasil, con pacientes con diagnóstico y tratamiento para la AF. Los datos fueron recogidos en mayo de 2014 a través de una entrevista a los pacientes con AF y sus respectivos representantes legales y realizadas en la sala de espera mientras esperaban la consulta médica en la institución. Se aplicó la siguiente pregunta guía: "Cuales son las principales precauciones realizadas por ti para la prevención de complicaciones de la AF?" Los datos fueron analizados según la técnica de Análisis de Contenido de Bardin.* ***Resultados:*** *Se evidenció que los pacientes no tienen un conocimiento exacto sobre su enfermedad lo que es una desventaja para los cuidados primarios. El diagnóstico de la enfermedad se da en general por la necesidad de intervenciones clínicas en repetidos episodios de dolor. Los eventos de dolor representan las principales dificultades y causas de ingresos hospitalarios en los servicios de urgencias.* ***Conclusión:*** *Las acciones de educación del equipo de salud multidisciplinario hicieron posible para el paciente con AF y su cuidador la mejoría de la asistencia a través de actividades y acciones de autocuidado.*

Descriptores: *Autocuidado; Anemia de Células Falciformes; Enfermería.*

INTRODUCTION

Sickle cell anemia (SCA) has been acknowledged to have a global public health impact[1] by the World Health Organization and United Nations. Over 300,000 babies are born worldwide annually with the Hb SS type of sickle cell disease (SCD) mostly in low- and middle-income countries[2].

This is considered the most prevalent hereditary chronic disease in Brazil[3], where its distribution is quite heterogeneous, being more prevalent in the North and Northeast regions, ranging from 6% to 10%, due to a higher number of African descendants, whereas in the South and Southeast regions the prevalence is lower, from 2% to 6%[4].

Because of its prevalence and clinical importance, sickle cell anemia is a public health problem in many countries[1,5], including Brazil. Also, it is a chronic disease characterized by clinical variability among patients and in the same patient, with periods of well-being interspersed with situations requiring urgent or emergency care[6].

The self-care practice should be shared with all health professionals, as a meeting between people, that is, a collective construction, believing that such practices can be changed from the disease-centered model to a model that favors the everyday practice of individuals and their families in the search for health care[7]. This prerogative is in accordance with the principles of Health Promotion in the population context, as it empowers people to take care of themselves by providing the necessary information for such. Based on the assumptions of the health promotion model, health education should be understood as a multifocal field that enables the exchange of information and the construction of a critical view of health problems[8]. Thus, educational processes should aim for the awareness and autonomy of the subjects.

From such perspective, the application of the general theory of nursing proposed by Orem emerges as a fundamental strategy, in which the importance of customer engagement in self-care is emphasized, in order to enable individuals, families and communities to take initiatives and assume responsibilities in the effective development of their own care toward improving the quality of life, health and well-being[9].

Given the scarcity of studies on the implementation of Orem's general theory of self-care in patients with sickle cell anemia (SCA), this study aimed to map the knowledge of self-care practices, held by patients affected by SCA and their caregivers at a Referral Center for Hematology and Hemotherapy in the southern region of Ceará state, Brazil, and draw a parallel between such knowledge and the assumptions of Orem's general theory of nursing.

METHODS

A cross-sectional and qualitative study was carried out in patients with laboratory diagnosis of sickle cell anemia in medical follow-up by the Hematology and Hemotherapy Center (HEMOCE), located in the city of Iguatu, central south region of the state of Ceará, Brazil.

Patients with other hemoglobinopathies, without clinical follow-up at the institution for more than six months, and those undergoing nosocomial hospitalization were excluded. Thus, of the 25 patients diagnosed with sickle cell anemia treated at HEMOCE in Iguatu, nine were selected, for authors' convenience and data saturation reasons, to participate in the study.

The data for analysis were collected in May 2014, and the interview was conducted with patients with sickle cell anemia or with their respective legal guardians, who were at HEMOCE on Wednesdays and Thursdays for routine consultation with the institution's hematologist. Thus, they were invited to participate in the study while awaiting medical attention.

Data collection was performed by means of a semi-structured interview with the aid of a mobile device, Motorola XT916, using the Voice Recorder app. The interview was recorded and conducted by the researcher individually with each patient or their legal guardian, with an average duration of forty minutes.

The variables investigated were: age, sex, skin color (self-declared), schooling, origin. The following guiding question was asked: "What are the main precautions you take to prevent the complications of sickle cell disease?" Data were collected by a single observer. This strategy was adopted to obtain greater accuracy in the reports.

Data were analyzed in three steps, as recommended by Bardin's Content Analysis technique: (1) pre-analysis; (2) encoding; (3) treatment, inference and interpretation of results[10].

For heuristic reasons and easy viewing of the findings, the data were grouped into the following thematic nuclei: (1) previous knowledge about sickle cell disease; (2) discovery of sickle cell anemia; (3) difficulties faced by sickle cell patients and their families; and (4) the act of caring for patients with sickle cell anemia.

The ethical and legal principles of the Declaration of Helsinki and Resolution 466/2012 of the Brazilian National Health Council were respected. This study was approved by the Ethics Committee on Human Research of the Regional University of Cariri, linked to the University of the southern region of Ceará State, Brazil, under opinion no. 872 135. The authorization from the HEMOCE of Iguatu for investigation with patients of that institution was requested through a Consent and Research Collaboration Agreement.

The study participants were informed about the proceedings and objective of this research by reading the Informed Consent Form - ICF and the Assent Form - AF, for those under the age of 18 years, followed by signing the Post-Informed Consent Form and the Post-Informed Assent Form.

RESULTS AND DISCUSSION

The study comprised five patients under the age of 10 years and four adult patients. Of the total sample, six were female and only two patients had completed high school. Since sickle cell anemia is a pathology that involves biological, psychological and sociocultural aspects, there is a need for modifications in the lifestyle and daily life of children and caregivers, and these changes are mainly focused on activities related to educational practices, given the impacts on their learning process and school performance[3].

As for the self-declared color, three were black and six, brown. Despite being present in people with different colors, sickle cell trait and anemia have a higher prevalence among the black and brown population in the country, which represents a class differentiation for the disease, since blacks and brown[1,2,5] are among the poorest of the Brazilian population and the groups that seek health care services the most.

In order to facilitate data visualization and discussion, the categorizies found were adopted as follows.

Previous knowledge about sickle cell disease

It was observed, in the speech of the subjects interviewed that, although they hold a more accurate knowledge about the disease, the theme is still confusing.

> *"[...] the doctor explained it to me, but I do not know for sure, the doctor says that I have acquired it from my father and my mother [...]" (SCA[1]).*
>
> *"[...] this is a hereditary disease, right? The child inherits it from the father and mother [...]" (SCA[2]).*
>
> *"[...] this is a genetic disease, right? We have to take precautions and treat it for life, you know?[...]" (SCA[4]).*
>
> *"[...] this is an anomaly in the blood, a defect in my red blood cells, whereas yours are normal, right? Mine are sickle-shaped" (SCA[8]).*
>
> *"[...] in the blood circulation, as it passes through more skinny vessels and ... the blood ... the red blood cells hook in the others, there is no more oxygen to other vessels and this causes pain [...]" (SCA[8]).*

Two patients revealed not having any more precise information regarding their pathological condition, a fact that directly affects their care conditions.

> *"No, I do not know what this disease is. What I know is that I struggle a lot ... but compared to the way he was, he is much better now" (SCA[5]).*
>
> *"No. No one has ever explained it to me yet [...] in the city where we live nobody talks about it" (SCA[7]).*

Because of the chronicity, a person with SCA requires constant attention and encouragement to the systematic adherence to treatment, which requires an efficient and comprehensive education health program, since the perception of the specific care needs of the ill person and their family may favor the recognition, by health professionals, of the adversities faced in daily life resulting from this condition, making it possible to mobilize resources to assist them in the necessary coping[11,12].

The care process includes understanding oneself and the other[13], and particularly the caregivers have greater responsibility with respect to knowledge, since care is directly related to challenging times and moments of weakness that must be overcome with acquisition of new knowledge, especially with the situation experienced in daily life.

This view is in line with the recommendations of the self-care theory proposed by Orem, which is based on the premise that individuals can take care of themselves and verifies the applicability of the model in various areas, as it provides the active participation of the user in their self-care, improving health outcomes and, consequently, their quality of life and well-being[14].

Discovery of Sickle Cell Anemia

The discovery of the disease is generally related to the patient's clinical conditions, which varies greatly. Signs and symptoms of SCA include hand-foot syndrome, chronic hemolytic anemia, vaso-occlusive crises, infections, acute chest syndrome (ACS), acute splenic sequestration (ASS), stroke, priapism and leg ulcers[15]. This reality is evidenced in the following statements, made by the the patients' parents or caregivers :

> *"[...] she was very young ... she was 6 months of age, then she began to have convulsion, fever and swollen wrist joints, [...] then her belly started to grow, grow, grow, without defecating, without urinating, without doing anything, [...]" (SCA[9]).*
>
> *"[...] she was always in hospital, with infection and fever ... her feet and hands were always swollen, right? [...]" (SCA[2]).*

Vaso-occlusive crisis (VOC), hallmark of sickle cell disease (SCD), is the primary cause of Emergency Department admissions and patients' hospitalizations. About 20% of all-age deaths in the United States occurred during VOCs, and more frequently for those 20–54 years old in an inpatient facility[16].

> *"[...] At 2 years of age [...] My mother says that it started with joint swelling and pain, then, the examination was made and it was discovered [...]" (SCA[8]).*

In Brazil, an advance in terms of early diagnosis of SCA and other hemoglobinopathies was brought by the Guthrie test, established by the Ministry of Health Government Decree no. 822, dated June, 6, 2001, which instituted the National Neonatal Screening Service[15]. However, only two of the nine patients with sickle cell anemia have discovered it through the newborn screening, as evidenced by the following reports:

> *"It was when she was born, I did the Guthrie test, then the result came ... pointing it out [...]" (SCA[6]).*
>
> *"Through the Guthrie test [...]" (SCA[4]).*

Neonatal screening, in addition to providing early detection of disease, enables the establishment of preventive measures to the health of these individuals, the provision of information to parents and family members, and access to the necessary knowledge for living with the specificities of SCA[4].

Despite the advances made in its first decade of existence, the Neonatal Screening Program, created in 2001, presents some challenges to be overcome, such as lack of coverage throughout the country; lack of health structure capable of ensuring the diagnosis and treatment of all newborns; and insufficient training of professionals to provide health education[17]. In this context, helping parents to understand the implications of having a child carrier of SCA can be a challenge for professionals in primary care, which sets an impasse to the introduction of the principles of Orem's theory of self-care[18].

Difficulties faced by sickle cell patients and their families

The painful events are the main difficulties and causes of hospitalizations with the search for emergency medical care services[3]. Pain severity is quite varied and can present from moderate and transient events (5 to 10 minutes) to the most severe, lasting from hours to days[19].

Repeated crises, associated or not to admissions, can trigger numerous psychological reactions in patients, particularly in children, as exaggerated attachment to caregiver, decreased self-esteem, decreased school performance, which may be associated with frequent absences and anxiety[3].

Thus, painful crises of vessel occlusion make a striking feature in the life of sickle cell patient, being largely responsible for various complications, limitations and changes in daily life. Thus, when asked about the difficulties, some respondents reported pain as the main obstacle, as shown in the following speeches:

> *" When I am in crisis ... I feel a lot of pain, then I think this is very bad, it is awful to be admitted and stay in pain" (SCA[9]).*
>
> *"Only pain, only the pain. Sometimes I feel all right, sometimes I feel bad [...]" (SCA[8]).*
>
> *"[...] he feels a lot of pain, he cries a lot, [...] For he is so tiny and cannot tell where it hurts, right?" (SCA[4]).*

Pain is considered the most dramatic clinical manifestation of sickle cell disease. The authors also observed that the frequent experience of SCA patients with complications of the disease directly affects the habits, desires and dreams of the individual and their families, associated with feelings of insecurity and fear, causing behavioral and social limitations[20].

"[...] I cannot carry weight... whenever I take weight; I get sick and go to the hospital [...]" (SCA[1]).

"[...] I cannot make much effort or put my body under much impact; these things cause pain" (SCA[8]).

"[...] she cannot be exposed to dust or to hot sun, and cannot come close to a child with a cold and even if she has contact with children with cold, she has to use mask, [...] when she gets home, she has to use some soap specially developed against bacteria, wash her little hands; she cannot put in the mouth everything she picks in hand [...]" (SCA[9]).

"[...] when it is cold, I warm her up well, because the cold brings pain, right? [...]" (SCA[2]).

Because this is a chronic disease, its treatment is lifelong and, in order to be successful, family members need to learn about the signs of complications, and act properly in different complications. Parents should learn how to prevent and recognize the pain crises, manage painkillers and other measures to relieve it, recognize early signs of infection and cerebral infarction, palpate the spleen and identify the splenic sequestration crisis, among other vital information for child survival[17,21].

"When I have headache I take my medicine and, every day, I take my medicine, which the doctor has prescribed, that is folic acid. For headache I take dipyrone" (SCA[9]).

"[...] I take my vitamin [...] sometimes, when I know that I will feel a little pain, I take a painkiller and I already remain still, laid, avoid doing a lot of effort, not to test the body, right? Not to trigger a greater pain" (SCA[8]).

Thus, the care guidance process based on the model proposed by Dorothea Orem becomes an action performed in concrete situations, able to positively affect the health and well-being of that individual[22].

The act of caring for patients with sickle cell anemia

The meaning of care is built by incorporating knowledge from different sources and orders that are being shaped by body experience[7]. The family, when it assumes the responsibility at home for the health care of its loved one, rarely receives training/qualification for the performance of this new task. Caregivers, when confronted with this new reality, most often do not feel they are sufficiently prepared to carry out the activities that involve in-home care[23]. Therefore, the daily contact with the characteristics of the disease, in addition to frequent visits to a health care facility, provides the carrier and the caregiver with knowledge directed to the clinical conditions that the SCA causes in these individuals. An example of this is the lines that follow:

"[...] a lot of pain, fever, and it hinders growth... it sometimes leaves some wounds in the leg, right?" (SCA[4]).

"[...]it causes pain... from blood infection, pneumonia [...]" (SCA[9]).

"[...] during the crises we feel pain, the feet and hands become swollen [...]" (SCA[1]).

This reinforces the need for the family to receive multidisciplinary intervention and promote their competence in relation to home care, as in a broader context, education provided to the family and the individual with essential SCA, and the teaching shows that care means being together with the child/family. Teaching becomes learning, in an effort to understand the other[17,18,24].

In this context, the principles of Health Promotion emerge, which, according to the Ottawa Charter (1986), constitute the process of empowering the community to work on improving their quality of life and health, including a greater participation in the control of this process[25]. And, taking into account that the actions that people perform on a daily basis to prevent, control or reduce the impact of conditions that are sensitive to their health characterize self-care[26], to understand and stimulate practices such as those advocated in Orem's general theory are the most genuine expressions of the applicability of Health Promotion precepts in patients with ACS. Thus, educational actions aimed at guiding and supporting the patient with SCA enable them to maintain self-care activities, and educational support is the best way to approach the individual to their pathological condition, besides providing knowledge for a better understanding, thus reaching proficiency and succeeding in applying which is recommended by Orem, that is, self-care[27].

Finally, as limitations of the present study we can point out the reduced sample, due to a limitation of the institution in which the research occurred, which has few visits of SCA patients and the difficulties in collecting the data itself, given the limitation of dates available for that.

FINAL CONSIDERATIONS

The application of Orem's General Theory of Nursing is empirically evidenced and used in part by caregivers and patients, who acquire information on the pathology, its repercussions, methods of treatment and symptom relief, throughout the health-disease process. However, the practice of self-care performed by the SCA carrier in the studied health service is still limited and needs further interventions, such as educational activities, aimed at raising awareness and training of families, and especially of health professionals, as they collaborate on care engagement and handling of difficulties, and act as educators by familiarizing these individuals with self-care techniques.

In this sense, the nurse becomes necessary to achieve self-care, working through the support-education process by guiding, supporting, encouraging and supervising the execution of this practice, which makes their participation essential in improving the quality of life of the individual with SCA and their families.

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First author's address:
Natália Bastos Ferreira Tavares
Universidade Regional do Cariri
Avenida Dário Rabelo, s/n
Bairro: Santo Antônio
CEP: 63.502-253 - Iguatu - CE - Brasil
E-mail: nataliabastosf@hotmail.com

Mailing address:
Jucier Gonçalves Júnior
Universidade Federal do Cariri
Rua Divino Salvador, 284
Bairro: Centro
CEP: 63180000 - Barbalha - CE - Brasil
E-mail: juciergjunior@hotmail.com