Nursing protocol for children with sickle cell disease in emergency room: a convergent-care approach

Protocolo de enfermagem à criança com doença falciforme na emergência: uma abordagem convergente-assistencial Protocolo de enfermería del niño con enfermedad falciforme en la emergencia: un enfoque convergente-asistencial

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ABSTRACT

Objective: to describe the methodological process of developing a nursing care protocol for children with sickle cell disease in the emergency room. **Method:** convergent care research, carried out in a public pediatric hospital in the state of Bahia, with 12 emergency nurses specialist. Data production took place between July 2020 and April 2021, with semi-structured interviews, observation in a field diary and convergence groups, according to the research phases: conception, instrumentation, scrutiny and analysis. **Results:** The final result was the construction of a nursing care protocol for children with sickle cell disease in the emergency room for use in the study field. **Final considerations:** the Convergent Care Research proved to be an excellent methodological procedure for intervention in the health service, whose nursing care protocol was based on the reflections of professionals on evidence-based practices, whose consensus can enable safe and quality care.

Descriptors: Sickle Cell Disease; Emergencies; Pediatrics; Nursing; Protocols.

RESUMO

Objetivo: descrever o processo metodológico de elaboração de um protocolo assistencial de enfermagem para crianças com doença falciforme na emergência. **Método:** pesquisa convergente assistencial, realizada em um hospital público pediátrico do estado da Bahia, com 12 enfermeiras da emergência. A produção dos dados ocorreu entre julho de 2020 e abril de 2021, com entrevista semiestruturada, observação em diário de campo e grupos de convergência, conforme fases da pesquisa: concepção, instrumentalização, perscrutação e análise. **Resultados:** O resultado final foi a construção do protocolo assistencial de enfermagem para criança com doença falciforme na emergência, para uso no campo de estudo. **Considerações finais:** a Pesquisa Convergente Assistencial mostrou-se como excelente procedimento metodológico para intervenção no serviço de saúde, cujo protocolo assistencial de enfermagem partiu das reflexões dos profissionais sobre as práticas baseadas em evidências, em que consensos podem possibilitar uma assistência segura e de qualidade. **Descritores:** Doença Falciforme; Emergência; Pediatria; Enfermagem; Protocolos.

RESUMEN

Objetivo: describir el proceso metodológico de elaboración de un protocolo asistencial de enfermería para niños con enfermedad falciforme en la emergencia. Método: se trata de una investigación convergente y asistencial, realizada en un hospital público pediátrico del estado de Bahía, entre 12 enfermeras de urgencias. La producción de datos se realizó entre julio de 2020 y abril de 2021, mediante entrevistas semiestructuradas, observación en diario de campo y grupos de convergencia, según las fases de la investigación: concepción, instrumentación, escrutinio y análisis. Resultados: El resultado final fue la construcción de un protocolo de cuidados de enfermería para niños con anemia falciforme en el servicio de urgencias, para su uso en el campo de estudio. Consideraciones finales: la Investigación Convergente Asistencial demostró ser un excelente procedimiento metodológico de intervención en el servicio de salud, cuyo protocolo de cuidados de enfermería surgió de las reflexiones de los profesionales sobre las prácticas basadas en evidencias, en las que el consenso puede permitir una atención segura y de calidad.

Descriptores: Anemia de Células Falciformes; Urgencias Médicas; Pediatría; Enfermería; Protocolos.

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INTRODUCTION

Sickle cell disease (SCD) is a public health problem, as it is one of the most frequent genetic alterations in Brazil and in the world, which causes several repercussions in the organism of individuals who live with this disease since childhood and throughout life⁽¹⁾.

The chronic condition of people with sickle cell disease permeates the presentation of several clinical manifestations, with organ impairment, functionality for daily activities, mobility and social life, which represents a life based on care since childhood in face of the need for treatment⁽¹⁾.

The National Policy for Comprehensive Child Health Care highlights in Axis VI of "Health Care for Children with Disabilities or in Specific and Vulnerable Situations", sickle cell disease as an important health problem for black children, which was elected priority by the Ministry of Health⁽²⁾.

At the level of care of the Urgency and Emergency Network, care for acute clinical complications occurs. These services must have trained professionals to care for people with SCD; as they often do not receive available care due to the professionals' lack of familiarity with the disease and the lack of connection between them and the reference centers⁽³⁾.

Thus, the nurses' fundamental role in caring for these patients in the various health sectors is highlighted, especially in the emergency room, as it can help to reduce the frequency and severity of crises and their complications through targeted practices of Caution. In addition, with the recognition of the nature of the occurrences and their treatment, longevity and better quality of life can be promoted for these patients⁽⁴⁾.

Thus, the object of study of the investigation was nursing

care for children with sickle cell disease in the emergency room, on which there is still a gap in the area of scientific knowledge, because when searching for the state of the art through the SciELO, LILACS and Virtual Health Library (VHL) databases, using the descriptors "sickle cell disease", "pediatric emergency", "hospital care" and "nursing", with Boolean "and", only three that referred to the care of children with sickle cell disease in the emergency room were found.

From this perspective, the research question-problem was defined: how to guide nursing care for children with sickle cell disease in the emergency room at a public pediatric hospital?

To develop the problem-question of this research, the Convergent Care Research (CCR) was chosen, as the method reinforces the need for convergence between nursing care and research with the objective of solving problems arising from daily practice, enabling changing actions and implementing innovations that can improve the quality of care for children with SCD in health services⁽⁵⁾.

The importance of this research concerns nursing care in pediatric emergencies, where the professional needs to be able to identify the risk factors presented by the child, assess their needs

to implement quality care and resolution. Thus, it will be able to provide a differentiated care, supplying the demands, which aims at an effective and welcoming care. Therefore, it aims to reduce the suffering of the people involved in the care process⁽⁶⁾.

OBJECTIVE

To describe the methodological process of elaborating a nursing care protocol for children with sickle cell disease in the emergency room.

METHODS

Ethical aspects

The research project was approved by the Research Ethics Committee on Human Beings of the Universidade Estadual de Feira de Santana, and had 12 nurses participating, upon signature of the Informed Consent Term (ICF).

Methodological framework

The study used the Convergent Care Research (CCR) method, whose main characteristic is the intentional articulation of research with care practice, whose design presents a methodological character of proximity and distance from the know-how care, which allows reciprocal exchanges of information throughout both processes⁽⁷⁾.

To illustrate the stages of Convergent Care Research to the research proposal, the methodological design was created (Figure 1), which demonstrates the phases that have passed.

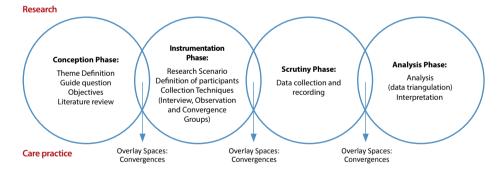


Figure 1 – Methodological design of the Convergent Care Research in the study

Study scenario

The study was carried out in a public pediatric hospital in the countryside of the state of Bahia, from July 2020 to April 2021.

It is noteworthy that the presentation of the steps that include data collection and organization will be in accordance with the methodological design of the CCR.

Conception

The first phase represents the choice of the theme, the direction of the guiding question, the establishment of the research

objectives, the literature review, the elaboration of concepts and assumptions, that is, it is the referential or theoretical framework⁽⁸⁾. Thus, this phase comprised the definition of the problem-situation of the nurse's daily life that needed to be rethought, so it was a phase of reflection on the theme with the objective of improving the quality of nursing care.

At this stage of the convergent care research, the state of the art was sought through the SciELO, LILACS and Virtual Health Library (VHL) databases, using the descriptors "sickle cell disease/ sickle cell anemia", "pediatric emergency", "care hospital" and "nursing", with Boolean "and".

Therefore, the scarcity of studies on the object of study delimited in the investigation was evidenced and the guiding question was constituted, which guided the reflection on nursing care for children with sickle cell disease in the emergency room and made it possible to propose a protocol to direct the care in this area.

For the construction of this protocol, the guidelines of Pimenta and collaborators⁽⁹⁾ were used and for the establishment of the principles, the suggestions of Titler⁽¹⁰⁾; were followed; which guide the methodological steps, as well as the technical apparatus for creating the protocol.

Instrumentation

It consists in the elaboration of methodological procedures, which includes the choice of research space, the choice of participants and the choice of technique for obtaining and analyzing information⁽¹¹⁾.

The study was carried out in the emergency department of a public pediatric hospital, in the countryside of the state of Bahia, a reference in this specialty in the country⁽¹²⁾, including children with sickle cell cells. The chosen scenario proved to be relevant for carrying out the problematic investigation about nursing care to those already enrolled.

Twelve nurses who had been working in the emergency department of the pediatric hospital for at least six months participated in the study (considering this time as the minimum time to have experienced the emergency context and, possibly, care for a child with SCD) and who voluntarily agreed to participate in the research through signing of the Informed Consent Term (ICF). The approach for the research with the participants took place by telephone, considering the current period of the pandemic.

Nurses on sick leave or vacation and/or absent from the sector during the data collection period were excluded.

Regarding the collection techniques, it is noteworthy that CCR allows the use of multiple data collection techniques, since it privileges the resolution of problems experienced in nursing practice and the selected techniques must converge to the research objectives⁽¹³⁾.

To make it possible to achieve the objectives proposed in the CCR methodology, the following collection techniques were chosen: Knowledge survey; Convergence Groups and Participant Observation.

The knowledge survey consists of an activity to assess the participants' knowledge, through instruments or interviews, which help the researcher to investigate the acquired content about the problem situation and the theme involved⁽⁶⁾. For this survey, a semi-structured individual interview was chosen.

After the application of individual interviews, Convergence Groups (CG) were formed, whose participants and researchers met with the objective of developing theoretical knowledge to benefit the care practice studied with the creation of the care protocol⁽¹⁴⁾. The CG allow the collective construction of knowledge on the subject and the participation of participants in the process of changing care practice.

Participant Observation is a fundamental part of the researcher's immersion in the research scenario, as it performs care practice activities, simultaneously records data for the research and includes the actors and their relationships in the observed context⁽¹⁴⁾.

Scrutiny

It includes the collection and recording of data, which are intended to obtain information with the dual intention of producing scientific constructions in research activities and favoring the improvement of the care provided by the Nursing team⁽⁸⁾.

In order to carry out the semi-structured individual interview, a script was used with the guiding questions and, prior to this, socio-demographic information was collected from the research participants.

As a result of the pandemic, data collection began in July 2020, after the release of the research field and through the adoption of measures to control the transmission of COVID-19.

Before starting the recording, the informed consent was read, doubts clarified and a copy was delivered to each participant. They chose random fictitious names that were not part of the emergency team, sociodemographic data were collected and the interviews were recorded in order to preserve the reliability of the data collected, always asked at the end if they wanted to hear the content or change something in the speeches.

The CG took place remotely through the Google Meet app, still in the context of the COVID-19 pandemic. To facilitate communication between the researcher and professionals, a group was created on the Whatsapp application, with prior authorization from each one, where meetings were scheduled, on two dates for each topic, in order to reach the largest possible audience.

Five CG meetings were held, lasting one hour each. The topics chosen for training and discussion of the groups were suggested by the participants in the interviews, from which emerged: the general aspects of sickle cell disease, the warning signs and severity and care for children with sickle cell disease in the emergency room.

The first meeting of the GC addressed "General aspects of sickle cell disease and its acute complications" and the second, "Nursing care for children with sickle cell disease in the emergency room", encompassing the topics suggested by the participants, with discussion directed towards the construction of the protocol. The fifth meeting – with most of the participants and nursing coordination – took place to present the first version of the protocol, structured by the researcher in accordance with the scientific discussions and suggestions of the participants in the CGs.

In direct observation - carried out in three days - the Observation Guide was used and it was possible to observe the flow of children treated in the emergency, with the presence of a child with SCD in just one day due to the reduction in the number of visits, including children with SCD during the pandemic.

Analysis

In CCR, the apprehension process begins with data collection with the organization and codification of information; the synthesis consists of subjectively examining the data and making associations and variations of the information found in the apprehension process. On the other hand, the theorizing process consists of discovering the values contained in the information collected during the synthesis process⁽¹¹⁾, as illustrated in Figure 2.

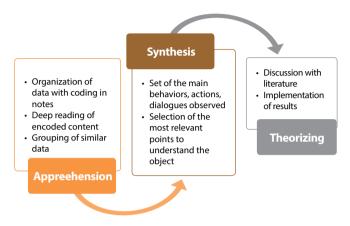


Figure 2 – Analysis process of the Convergent Care Research on nursing care for children with SCD in the emergency room

RESULTS

In order to create a protocol, continuing education on the subject with the team becomes essential, in order to provide theoretical-practical subsidies, with active discussions among health professionals. So, after this step, the aspects that make up the standardization of care were collectively listed, according to the CCR.

The main suggestions of the participants encompassed the standardization of care through the inclusion of signs and symptoms of SCD targeted in the Reception with Risk Assessment and Classification (RRAC) system, since there was none in the current program; or prioritize this audience as "orange" for faster start of care; use of the pain scale for evaluation; application of the Pediatric Alert Score (PAS), already implemented in the hospital for hospitalized children, in children with SCD under observation in the emergency medication room to assess clinical deterioration and severity; and periodic oximetry, if continuous oximetry is not prescribed to monitor the saturation and oxygenation levels of affected children.

In CCR, in addition to the phases already illustrated, the transfer process takes place. This constitutes the transfer of the results obtained in two aspects, one related to the research scenario and the other one in the expansion of the results for reflection in similar contexts^(11,13). In this process, the construction of a protocol for the care of children with SCD in the emergency was used as a strategy.

Simultaneously with the scrutiny phase, in the analysis phase, the contents of the interviews, convergence groups and observation were analyzed, synthesized and the care protocol was prepared by the researchers in the form of text and flowchart.

For this, we chose to follow the graphic methodology described by Pimenta et al $^{(9)}$.

The instrument was built based on national and international scientific literature, in the format of a Standard Operating Procedure (SOP) used by the hospital that constituted the field of this CCR and according to the model described by Titler⁽¹⁰⁾, which defines the main items of a protocol: the subject; purpose or objectives; necessary equipments; procedures with the detailed actions to be developed; precautions; and references that support the practice.

Thus, the built protocol contains: title; responsible professional; objective; definition of sickle cell disease, with brief pathophysiology and clinical manifestations, preparation and necessary materials; detailed procedure with the actions to be performed by the nurse in the RRAC, Medication and Inpatient Room; recommendations; bibliographic references; and flowchart of care for children with sickle cell disease in the emergency room with warning signs. These elements give consistency and objectivity to the actions planned for care aimed at the public to which it refers.

The Protocol was presented to the research participants and to the hospital and emergency nursing coordination's, and there was a discussion for possible modifications, in order to make its implementation easier, among which the definition of priority in care through the "orange" identification bracelet for patients who show warning signs of the disease.

After accepting the suggestions and modifications, the final version of the protocol was sent back to the coordination of the sector for approval, before starting the training to use the instrument and its implementation in the service, without changing this final version.

DISCUSSION

When analyzing the CCR process, especially through the implementation of the Convergence Groups, the active participation of nurses in the elaboration of the protocol is perceived, since they were the professionals involved in the direct care of children with SCD in the emergency, signaling the importance of CCR for the elaboration of protocols aimed at changes in care.

Considering the context of the study field, in the State Protocol for Risk Classification of the Bahia State Secretariat, the child with sickle cell anemia appears only in the item of abdominal complaints, in which a red classification is recommended for the child⁽¹⁵⁾, so it is an adapted version of Manchester and does not use the color "orange".

On the other hand, in the Manual of Reception and Risk Classification of the Federal District⁽¹⁶⁾ there is a section for classifying patients with sickle cell anemia and hemophilia. In this one, intense pain (7-10/10) is described, such as abdominal, chest, limbs, lumbar pain, without response to the use of analgesics; persistent and painful erection; temperature $\geq 38^{\circ}\text{C}$; increase in joint volume with difficulty in mobilizing the limb, which may have phlogistic signs (edema, heat, erythema and pain); dyspnea; hemiparesis; acute neurological impairment; frequent vomiting; sudden increase in pallor associated with weakness and hypoactivity, and/or sudden enlargement of the abdomen; and jaundice with abdominal pain, listed as "orange" signs and symptoms.

In addition to highlighting the patient with SCD in fever and infections, shortness of breath and respiratory symptoms and pregnant women. Jaundice without fever or pain, mild to moderate pain (4-6/10) in extremities, associated with edema, improves with analgesics; neurological deficit with motor deficit (paresis or paralysis) for more than 24 hours; temperature $> 37.5^{\circ}c < 38^{\circ}c$; and hematuria, it is classified as "yellow" (16).

This demonstrates a better articulation of the state with the health policy of the population with SCD and presents care measures that prioritize the care of this public, especially when using the color "orange" to shorten the waiting time. In Bahia, however, there is a need to reformulate the care policy, as well as update the risk classification manual to better guide the management of these patients.

Thus, the protocol developed considers the signs and symptoms of risk in the assessment of children with SCD and indicates the use of the orange label in the care forms generated after the RRAC of children with SCD and warning signs of the disease, as a way of adapting care to the needs of the target audience.

It is also suggested⁽¹⁷⁾ the use of specific and validated measurement instruments in the investigation and understanding of SCD-related aspects; constituting an important work tool for health professionals involved in the context of sickle cell disease. Thus, the protocol developed reinforces the importance of using the pain scale, as well as the evaluation of clinical deterioration by the Pediatric Alert Score (PAS) with children with SCD.

Pain scales are relevant instruments in the assessment of children with SCD and should be used from the moment the child arrives at the unit during the RRAC, as well as throughout their stay in the emergency room, with continuous evaluation and reassessment of the treatment and care provided. In a study, after educational interventions, the high pain score in the triage was attributed more frequently, the waiting time in the administration of analgesics was reduced and the use of the Visual Analogue Scale increased⁽¹⁸⁾.

The Pediatric Alert Score is a risk predictor already implemented in the study field, it can be used even in outpatients to predict, identify severity and anticipate prevention and control measures⁽¹⁹⁾. In a study on the accuracy of the aforementioned alert score, for the Brazilian context, the results showed good performance and it was considered valid for the recognition of warning signs of clinical deterioration in the children studied⁽²⁰⁾.

On the other hand, regular oximetry is recommended by the Ministry of Health⁽²¹⁾. According to the National Heart, Lung and Blood Institute⁽²²⁾, based on evidence, it is recommended to start analgesic therapy quickly 30 minutes after screening, or 60 minutes after pain recording. The recent international Guideline also recommends rapid analgesia within 30 minutes after clinical evaluation⁽²³⁾. Thus, the use of oximetry is recommended for children with periodic SCD every 6 hours, if they do not have continuous oximetry, immediate venipuncture for drug administration and intravenous hydration, as ordered by the doctor, and rapid onset of analgesic therapy.

Therefore, we noticed that CCR allows a series of strategies, among which the protocols, which - when well ordered - transmit the knowledge produced in the research in an accessible language for users and professionals unfamiliar with the theme⁽¹¹⁾.

The use of protocols contributes to improving care, favoring the use of scientifically supported practices, minimizing the variability of information and conduct among members of the health team, as well as establishing limits for action and cooperation between the various professionals⁽⁹⁾.

In a previous study⁽²⁴⁾ to implement a protocol in the care of children with SCD in the emergency room, the results showed significant improvements in the time from screening to administration of the first analgesic; increase in percentage of: patient visits who received pain medication within 30 minutes of screening (from 7% to 53%); assessed within 30 minutes of screening (from 64% to 99.4%) and reassessed within 30 minutes of initial analgesic (from 54% to 86%).

This contrasts with unsystematic assistance for children with SCD, which indicates that about 25% of people who visited the emergency room reported that health professionals did not spend enough time with them, and their children did not receive prompt care⁽²⁵⁾. Thus, care to children with SCD – through a systematization or protocol – must classify properly, rapid onset of analgesia, periodic visits and cyclical reassessments⁽²⁵⁾.

In a survey carried out in Nigeria on the patterns of pediatric hospitalization and predictors of prolonged hospitalization in the children's emergency room, it was concluded that children admitted for SCD in the emergency had greater chances of prolonged hospitalization and that prevention and adequate management of sickle cell disease can reduce these rates (26).

With the need for advances in care for people with SCD, especially for children in emergency situations, the construction of the protocol with a flowchart of care constitutes a technology to be implemented with the ability to standardize and direct nursing actions in care, according to public needs and service possibilities.

In a study on the shared construction of the care protocol for women in the process of parturition with CCR, it made it possible to identify and understand the barriers and weaknesses in the care process, reflect and discuss possibilities to guide the actions of each professional involved⁽²⁷⁾.

Thus, the importance of CCR is reinforced as an appropriate method in the construction of the care protocol⁽²⁸⁾, with a significant contribution to the approximation between theory and practice; in addition to the active participation of the participants during the research, which results in their support and agreement on the proposal for transformations and improvements to the work environment based on the researched theme, as reaffirmed by other studies carried out with the aforementioned methodology⁽²⁹⁻³⁰⁾.

Limitations of the study

As a limitation of the study, there is the impossibility of gathering the participants in all the convergence groups and moments of discussion, due to the pandemic and the nurses' own work regime, of which the fulfillment of the work schedules in more than a link. In a pandemic, in which the barriers imposed by social distancing and preventive measures against the spread of COVID-19 must be respected, carrying out the research was undoubtedly a challenge for the researchers and interviewees.

Contributions to the Area

The study was relevant for contributing to nursing professionals to improve the care provided to children with sickle cell

disease in the emergency unit, in order to generate interventions; collaborate to promote recovery, quality of life and well-being of patients with sickle cell disease and their families.

FINAL CONSIDERATIONS

The construction of a protocol for the care of children with SCD in the emergency is a technology capable of producing improvements in health practices in the study field. Thus, the Convergent Care Research proved to be an excellent methodological procedure for intervention in the health service, with the transformation of actions based on the intertwining between research and care.

In addition, when performing the CGs, it can be confirmed that they represent a facilitating element for the development of theoretical and scientific knowledge on the subject, as well as for the active participation of nurses in the construction of the protocol and in the implementation of changes in care practice.

There are still few studies in Brazil and in the international scenario that deal with nursing care in pediatrics, especially with the use of care protocols. It is recommended to include the topic in the subjects of undergraduate courses in health, to carry out new studies in the field of nursing, with a view to expanding scientific production and substantiating care practices that meet the needs of children with SCD and their families.

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