Revista
Brasileira
de Enfermagem
REBEn

THEMATIC ISSUE:
HEALTH OF WOMAN AND CHILD

RESEARCH

The pain of children with sickle cell disease: the nursing approach

A dor da criança com doença falciforme: abordagem do enfermeiro

El dolor del niño con enfermedad falciforme: el abordaje del enfermero

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How to cite this article:
Campelo LMN, Oliveira NF, Magalhães JM, Julião AMS, Amorim FCM, Coelho MCVS. The pain of children with sickle cell disease: the nursing approach. Rev Bras Enferm [Internet]. 2018;71(Suppl 3):1381-7. [Thematic Issue: Health of woman and child] DOI: http://dx.doi.org/10.1590/0034-7167-2016-0648

Submission: 02-03-2017 **Approval:** 11-02-2017

ABSTRACT

Objective: To describe how nurses identify the pain in children with sickle cell disease (SCD) and to list the strategies used by them in the evaluation and control of pain. **Method:** This is a qualitative, descriptive and exploratory research, performed through semi-structured interviews with 13 nurses. The interviews were transcribed and after this process the qualitative data were organized according to thematic analysis. **Results:** This study showed that the nurses can identify pain in children with SCD from the signals they emit, such as: constant crying, restlessness, facial expressions and verbal reports. Pain is difficult to evaluate due to the lack of instruments, such as a pain scale. For pain control they use emotional support, promotion of comfort and the administration of drugs prescribed by the doctor. **Final considerations:** The nurses recognize the pain of the child and use pharmacological and non-pharmacological methods to control it but have difficulties to assess it.

Descriptors: Anemia, Sickle Cell; Child; Pain; Pediatric Nursing; Nursing Care.

RESUMO

Objetivo: Descrever como o enfermeiro identifica a dor na criança com doença falciforme (DF) e pontuar as estratégias utilizadas por ele na avaliação e controle da dor. **Método:** Pesquisa qualitativa, descritiva, exploratória, realizada por meio de entrevistas semiestruturadas com 13 enfermeiros. Após transcrição das entrevistas, os dados qualitativos foram organizados segundo análise temática. **Resultados:** Evidenciou-se que os enfermeiros são capazes de identificar a dor em crianças com DF a partir dos sinais que elas emitem, como: choro constante, inquietação, expressões faciais e relatos verbais. A dor é difícil de ser avaliada devido à falta de instrumentos, como a escala de dor. Para o controle da dor é utilizado apoio emocional, promoção de conforto e administração de fármacos prescritos pelo médico. **Considerações finais:** Os enfermeiros reconhecem a dor na criança e utilizam métodos farmacológicos e não farmacológicos para controlá-la, porém têm dificuldades em sua avaliação.

Descritores: Anemia Falciforme; Criança; Dor; Enfermagem Pediátrica; Cuidados de Enfermagem.

RESUMEN

Objetivo: Describir como el enfermero identifica el dolor en el niño con enfermedad falciforme (EF) y puntuar las estrategias utilizadas por él en la evaluación y en el control del dolor. **Método:** Investigación cualitativa, descriptiva, exploratoria, realizada por medio de encuestas semiestructuradas con 13 enfermeros. Después de la transcripción de las encuestas, los datos cualitativos han sido organizados según el análisis temático. **Resultados:** Se ha evidenciado que los enfermeros son capaces de identificar el dolor en niños con EF desde las señales que ellas emiten, como: el llanto constante, la inquietud, las expresiones faciales y los relatos verbales. El dolor es difícil de ser evaluado debido a la falta de instrumentos, como la escala de dolor. Para el control del dolor es utilizado el apoyo emocional, la promoción de comodidad y la administración de fármacos prescritos por el médico. **Consideraciones finales:** Los enfermeros reconocen el dolor en el niño y utilizan métodos farmacológicos y no farmacológicos para controlarla, sin embargo, tienen dificultades en su evaluación.

Descriptores: Anemia de Células Falciformes; Niño; Dolor; Enfermería Pediátrica; Atención de Enfermería.

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INTRODUCTION

Sickle cell disease (SCD) is of African origin and is one of the most common hereditary hematological diseases in the world^(1)^. The predominance of this disease in Brazil is on the Northeast and Southeast regions, being more common in the black population and their descendants^(2)^. In Brazil, 3,000 children are estimated to be born with sickle cell disease per year; among these children, 80% do not reach five years of age due to complications of the disease and not receiving the necessary health care^(3)^.

SCD is characterized by a type of mutant hemoglobin known as hemoglobin S (HbS), which causes the distortion of erythrocytes, giving them a sickle shape^(1)^. The detection of the disease is made by neonatal screening tests, seeking an early diagnosis. This allows the specific care required by a degenerative disease to start^(3)^.

Usually, the clinical picture of SCD starts from six months of age. The most common signs and symptoms are acute pain or vaso-occlusive crises, ulcers on the lower limbs, jaundice, pallor and fatigue^(1)^.

The first vaso-occlusive crisis, also known as hand-foot syndrome, occurs within the initial months of life, being characterized by pain and swelling in the back of the hands and/or feet, sometimes accompanied by erythema and localized warmth^(4)^. This crisis is the greatest clinical manifestation of the disease, being caused by the occlusion of small blood vessels by the sickle-shaped erythrocytes^(5)^. This is recognized as a mark in the life of the patient, which explains the remarkable demand for emergency care and hospitalization^(4)^.

Regarding the recognition of pain in children with SCD some difficulties for caregivers (parents and health professionals) can be highlighted, since these children of very young age may lack the cognitive abilities or the vocabulary to report or describe their pain^(6)^.

The identification of these painful events is based on the cognitive development of each child. Until two years of age, the evaluation criteria adopted are physiological and behavioral aspects; from this age, the reports of the child about their own experiences can be used to evaluate the intensity or severity of the pain crisis, the use of appropriate instruments, such as pain scales is also possible^(7)^.

In addition to drug therapy, non-pharmacological strategies (such as emotional support and promotion of comfort) are also useful to control, treat and help with the recovery of the child.

Thus, care given to children with SCD during their painful experience requires skills from the nurses to identify, evaluate and control the pain, always considering the age and the subjectivity of each child when facing their behavioral reactions, for an integral and humanized care. Given this discussion we question: how a nurse identifies the pain in children with SCD? What are the strategies used to evaluate and control the pain?

OBJECTIVE

To describe how a nurse identifies the pain in children with SCD and to list the strategies used to evaluate and control the pain.

METHOD

Ethical aspects

This study was performed in accordance with the standards and guidelines for research established by Resolution No. 466/12 of the National Health Council^(8)^. The participants received and signed an Informed Consent Form, which ensures the anonymity and freedom of refusal or exclusion in any phase of the research. The participants were identified by the letter I (for interviewee) followed by an Arabic numeral, which corresponds to the sequential order of the interviews (from I1 to I13). This study was approved by the Research Ethics Committee of the Centro Universitário Uninovafapi.

Type of study

This is a descriptive and exploratory study, with qualitative approach. Qualitative research is based on a reality not quantified, which involves meanings, motives, beliefs, values and attitudes, i.e., it deals with the subjective, varying from person to person, and it may suffer influence from the environment. The results were analyzed using the theoretical framework proposed by Minayo^(9)^.

Methodological procedures

Study scenario

The study was performed in a state pediatric hospital located in the city of Teresina, Piauí, Brazil, this institution is reference in the treatment of children with SCD. This hospital receives patients exclusively from the Unified Health System, currently there are 76 inpatient beds and 9 beds for Intensive Care Units, providing pediatric care in the areas of surgery, hematology, nephrology, rheumatology, neurology and intensive care. The average monthly hospitalizations of children with SCD is of three. The scenario was defined as the inpatient unit, which has nurses in its staff.

Data source

The participants were 13 nurses (part-time and full-time nurses) selected by random probability sampling – in which all elements of the population have the same probability of being chosen as a sample element –, through a drawing of the monthly scale of the inpatient sector. We included nurses working for at least one year and regardless of sex and chose these criteria because the professional would be more used to child care, having more knowledge about the study subject. Nurses who were on vacation and on paid live during data collection were excluded.

The number of participants was chosen during the research, since the criteria for interruption of data collection was the saturation of data, defined as the suspension of new participants from the moment that the data showed redundancy^(10)^. Considering the inclusion, exclusion and saturation criteria, the representativeness of this study was of 43.3%, from the total of 30 nurses in the research field.

Data collection and organization

The data were collected during February and March 2016, through a semi-structured interview script. The first step of the process was inviting potential participants – if the invitation was accepted we scheduled an appointment. The collection was performed individually, by the author, in a private environment at the end of the workday of the participants. We note that there were no previous links between the participants and the authors.

The instrument was organized with open and closed questions. The closed questions were intended to characterize the nurses, and the open to meet the research objectives. The average duration of the interviews was 30 minutes. The questions were made orally, and the answers were recorded using a cellphone with permission of the participants, and fully transcribed later.

Data analysis

This process was based on thematic analysis, the objective of this method is to establish an understanding of the data collected, to confirm or not the objectives of the research. The method also extends the knowledge on the researched theme by associating it with the cultural context(9). The data collected were described, interpreted and organized into thematic units to be analyzed in comparison to the theoretical basis used. The thematic units were: identification of the pain of the child with sickle cell disease by the nurse; strategies to evaluate and control the pain of the child; and impact of "pain and hospitalization" on the daily life of the child.

RESULTS

Characterization of the nurses participating in the research

The participants of this study were 13 nurses, 4 men and 9 women, aged between 23 and 44 years, and service time in pediatric care ranging from 1 to 22 years. Among the professionals, three had no graduate course, and only one was an expert in the pediatric area. The other nurses had graduate courses in family health; intensive care unit (ICU); nursing care guidelines for non-communicable chronic diseases; educational management and epidemiology.

Identification of the pain of the child with sickle cell disease by the nurse

The interviewees identify the pain of the child and report crying, restlessness and verbalization as the main forms of manifesting it:

> *We realize the crying immediately; the child begins to cry and complain of pain.* (I1)
>
> *They can also mention the pain when they are children who already verbalize things.* (I2)
>
> *Restlessness and hard to control crying are the most identified aspects.* (I3)

Children use verbal or non-verbal forms (such as behavioral manifestations) to interact with the environment and express their complaints of pain. In this perspective, the participants cited crying, discomfort, irritation, restlessness and the expressions of suffering as behavioral manifestations:

> *When the child is uncapable of engaging in dialogue, the crying and the discomfort can tell us something.* (I4)
>
> *Usually the child does not seem to be feeling well, and may be tearful, angry and restless.* (I2)
>
> *The medics request the opinion when the child is too tearful and irritated.* (I5)
>
> *An important resource to be used is the dialogue with the mother, to identify behavioral changes that are characteristic of pain, like facial expressions of pain.* (I2)

For the professionals interviewed, physical examination can also help identify pain in children with SCD:

> *First, we assess where the pain is located.* (I5)
>
> *Depending on how you approach and establish physical contact with the child, he/she will be more open.* [...] *we also use palpation on smaller children, and if the child is crying even palpation is not needed sometimes.* (I1)
>
> *There are situations in which the child points the location of pain, for example, placing his/her hands on the abdomen.* (I2)

The participants also highlighted that physiological changes, such as drops in oxygen saturation and increased cardiac and respiratory rates, can indicate pain in children:

> *Children with special needs or aphasic may present changes to vital data, such as tachycardia or oscillation of oxygen saturation.* (I2)
>
> *I consider a complaint of severe pain, which often changes the child's vital signs, and may cause dyspnea and tachycardia.* (I6)

Strategies to evaluate and control the pain of the child with sickle cell disease

The strategies and therapies used for pain relief of children with SCD can be pharmacological and non-pharmacological. They must be chosen according to the needs of the patient and pain intensity during each episode. For this thematic unit, the nurses reported pharmacological therapy as the most used strategy:

> *At hospital level our main intervention is through drug therapy* [...] *and if the intensity of pain increases we contact the medical professional.* (I2)
>
> *We communicate the emergency doctor for evaluation and prescription of analgesics, anti-inflammatory drugs and opioids, if these were not prescribed.* (I4)
>
> *My experience is with inpatients, so what I do to relieve the pain is to administer the prescribed drugs.* (I7)
>
> *If I had contact with the inpatients I would administrate the prescribed analgesics.* (I8)

On the other hand, some professionals expressed their skills in using non-pharmacological strategies when trying to ease the suffering of children during a painful crisis, such as recreation, dialogue and providing emotional support:

> *We end up using recreation, we do not have much material or instruments for this, but then we adapt to what we have. They like the latex gloves, so we fill them with air and play with them like a balloon* [...] *It's a matter of being playful and talking to them* [...] *Showing affection or speaking to the older [children] and with the younger I use the recreational part, it is easy to help.* (I1)

> *I try to relax the child with words like "you will get better soon" or "the pain will pass soon".* (I9)

> *You need to provide a lot of support, affection and understanding to the child.* (I7)

> *First, we talk a lot with these children, we know how severe their pain is, so we talk, we try to ease it.* (I5)

The interviewees reported pain scales to assess the pain of the children with SCD, however, one of the participants mentioned the name of a scale to classify injuries by pressure, and not to measure pain. In addition, according to the interviews, the institution does not own or offers an instrument of scale for pain assessment:

> *Here we do not use any formal written pain scale, like the Braden Scale. If there is one, no one showed it to me* [...] *We have the SAE* [Systematization of Nursing Care – Sistematização da Assistência de Enfermagem] [...], *but not a pain scale.* (I1)

> *The nurse must apply a pain scale to understand the symptomatology.* (I2)

The participants reported some strategies used to promote the comfort of children in the hospital, seeking to provide some improvement during the crisis:

> *I provide a comfortable and quiet environment for them, encouraging them to hydrate and to rest on the beds, identifying the precipitating factors of pain and stimulating walking when possible.* (I10)

> *Sometimes, staying hydrated helps with pain in sickle cell disease.* (I4)

> *I try to promote their comfort, to minimize the noises.* (I2)

> *I cherish the child* [...] *making the bed and the environment as comfortable as possible.* (I6)

Impact of "pain and hospitalization" on the daily life of the child with sickle cell disease

For some participants, the combination of "pain and hospitalization" results in the impairment of the quality of life of the child by reflecting on their daily activities, as shown in the following reports:

> [the child is] *unable to have a normal life, studying and playing.* (I11)

> *What I see is that these children always need interventions during their treatment, like blood transfusion and the treatment of their symptoms, this takes their leisure away etc.* (I7)

> *The pain causes negative impacts on child development, often increasing the period of hospitalization.* (I10)

The nurses highlighted the isolation, sadness and the denial of needed procedures and of the team providing care as manifestations of the dissatisfaction of the child with his/her reality:

> *There are some* [children] *that deny the medication or the access* [device], *in these cases we need to call this psychological support.* (I5)

> *The psychological aspects can cause sadness, isolation, and other things to the child.* (I12)

The participants highlighted the importance of the professional skills to support the child and to learn to identify the constant feelings that appear in these conditions:

> *The care provided cannot be focused only on the pain itself, but also on the psychological aspects that can cause the child sadness, isolation, among other things.* (I12)

> *The performance of the health care team is critical, especially to support the caregiver.* (I6)

> *The affection of the nursing staff helps to ease the pain caused by the disease.* (I13)

> *We must approach the child, so they can feel safe in relation to the professional.* (I12)

DISCUSSION

The interviewed nurses recognize that children with SCD use verbal or non-verbal communication and identify their crying and complaints as the most common manifestations. For younger children, the methods to assess the pain are: observation of facial expressions, irritation and moaning; for older children: verbal reports and restlessness.

Verbal report is the most used method when assessing the pain of a patient. However, this is a method based on the ability of the individual to communicate his/her symptoms, thus, assessing the pain of children who do not speak yet is more difficult(11).

If the intensity of the vaso-occlusive crisis is more accentuated, even a child who is capable of verbally communicating the pain can resort to crying as a form of expressing it. In addition to showing discomfort, this act may come from fear, since the child lived painful experiences in previous crises(3,12).

Thus, we can understand that children are the best information sources on their own experiences(13). They can expose their thoughts and feelings verbally or non-verbally, for this reason the nurse must participate of their world and help them on the situations they go through(14).

The participants also mention physical examination as a form of recognizing pain in children with SCD: the location of the pain and palpation are steps described by I1, I2 and I5 during the evaluation of the child undergoing a pain crisis. Physical examination is a step during nursing care planning that seeks to evaluate, through signs and symptoms, abnormalities that may suggest problems in the process of health and illness. The nurse must perform a careful and systematic evaluation, in the cephalocaudal direction, using the propaedeutic techniques: inspection, palpation, percussion and auscultation(15).

The intensity of sickle cell pain varies for each patient and age(4), being described by children as "very painful" or "non-stop pain"(16). Preschool and school-age children usually report the pain on their limbs, while adolescents report pain on the abdomen(5). Thus, the professional performance must be systematic, using the appropriate language and terms for each age group so the patient can cooperate, consequently, reducing the painful reactions(6).

The nurses mentioned some physiological changes as indicative of pain in children with SCD (decrease in oxygen saturation, increase on the respiratory rate and heart rate). The autonomic nervous system activates compensatory mechanisms when reacting to pain, creating responses such as increasing respiratory rate and heart rate, decreasing oxygen saturation, sweating and peripheral vasoconstriction(6). Pain causes noticeable imbalances in the body, which requires immediate intervention. The continued presence of pain can create significant reactions, including compromising the life of the patient.

The interviewees reported the use of the following strategies regarding the control of pain in children with SCD, pharmacological (drug therapy) and non-pharmacological therapies, such as recreational activities, dialogue and emotional support. Combining pharmacological and non-pharmacological therapies involves a humanized care to children, showing the holistic care capabilities of the team and not only the technical methods. Involving the family during the procedures is also important(17).

Playing does not stop the pain, but it helps the child to release feelings of anxiety, anger, hostility, fear and despair, easing the negative feelings of hospitalization and intensifying the recovery(18-19). Thus, the use of recreational activities such as games, toys, storytelling and dialogue, serves as the foundation for a nurse-child relationship based on trust(20).

Regarding the evaluation of the pain of children with SCD, the lack of contact and knowledge of pain measurement instruments was noticeable, especially considering I2, who cited the Braden scale as a pain scale; the scale mentioned is used to classify injuries by pressure, not pain, showing the confusion of the participant. According to the interviews, the institution does not own or offers an instrument to assess the pain of children with SCD.

Pain is considered a subjective experience, which cannot be measured by physical instruments, but it can be assessed by scales used in health services(21). Flaws may occur in the interpretation of pain if these scales are not applied during hospitalization, which would interfere on the effectiveness of the treatment. To promote pain relief of the patient, the nurse must be capable of assessing the pain, identifying the aggravating factors, implementing strategies for its control and monitoring the results of these interventions(22).

Pain is considered the fifth vital sign and health services must encourage and monitor the professionals regarding the assessment of pain as a vital sign, as well as the use of pain scales. Health services must seek to relieve a suffering that is often manageable(23).

The nurses mentioned some methods used to promote the comfort of the child during a painful crisis: offering a peaceful environment, minimizing the noise, encouraging bed rest, stimulating walking when possible and encouraging hydration.

When hospitalized, the child accumulates several sufferings such as pain, the separation and the physical discomfort caused by the intense manipulation and disease, thus, affecting their affective, emotional and psychological areas(13). Recognizing such suffering is critical for the nurse, so he/she can offer a comfortable and welcoming environment for the pediatric patient. According to the interviewed professionals, the impacts of "pain and hospitalization" on the routine of children with SCD compromise their quality of life. Which reflects on the daily activities they perform, such as study and leisure.

Some studies on the consequences of painful crisis of children who have SCD found that, for both the child and the caregiver, pain causes a great impact on various moments of everyday life(5,24). Therefore, the limitations of daily activities, the difficulty to control painful episodes and the severity of symptoms can trigger internal problems on the child, such as isolation, sadness, denial and the difficulty of social adaptation(11).

The nurses emphasized the importance of professional skills that help to provide support and to identify these feelings that arise during the hospitalization of children during sickle cell pain episodes. They highlighted caring methods that focus not only on pain itself, but on the psychological aspects, providing attention for the caregiver and transmitting safety to the child.

From our results, we can understand that the nurses identify the pain of children with SCD through verbal or non-verbal communication, using pharmacological and non-pharmacological strategies to relief the pain crisis caused by SCD. However, the nurses show a certain "knowledge frailty" regarding the assessment of pain, not being used to instruments such as pain scales.

Study limitations

The limitations of this research were the refusal from three professionals to be interviewed (from the 30 selected), and one of the nurses reported little contact of the professionals with children with SCD during a painful crisis.

Contributions to the field of nursing, health, or public policies

This study intends on contributing to the training of nurses, serving as guide in the care for children with SCD, when being hospitalized due to a painful crisis. The nurse professional must be trained to recognize the pathological process of SCD to intervene effectively.

FINAL CONSIDERATIONS

The interviewed nurses identify the pain of children with SCD through signals that they show, such as the constant crying, restlessness and facial expressions, as well as the verbal report in cases of older children. However, the nurses had no instruments to assess pain in their workplace, which can lead to issues during the therapeutic process.

Among the strategies to control pain mentioned by the professionals we can highlight the emotional support, the promotion of comfort and especially, the administration of the drugs prescribed by the medical professional.

This study allowed us to broaden the scientific evidence regarding the identification, assessment and control of pain of children with sickle cell disease by the nurse. Thus, this research can contribute for the professional to reflect on his/her practice, considering that, without a good assessment there is no good intervention, and that without a proper control of pain, the hospitalization processes will be prolonged and more traumatizing for the patient.

We recommend new research on the nursing approach of children with sickle cell disease during a pain crisis, since most of the literature on this theme is focused on adults.

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