

HOME-BASED MEDICATION THERAPY: EXPERIENCES OF MOTHERS OF CHILDREN AND ADOLESCENTS WITH SICKLE CELL ANEMIA

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ABSTRACT: Objective: describe the experiences of mothers of children and adolescents with sickle cell anemia with regard to home-based medication therapy. **Method:** descriptive study with qualitative data analysis, developed in September 2016. Eight mothers of children and adolescents under treatment for sickle cell disease were interviewed at the Pediatric Inpatient and Outpatient Service of a tertiary hospital in the state capital of São Paulo. The data were organized, coded and presented in categories, following content analysis procedures. **Results:** the mothers presented lack of knowledge on care during home-based medication administration, as well as on possible adverse effects, the action mechanism and benefits of the medication used. **Conclusion:** nurses need to act in advising the mothers for safe and correct drug administration at home, with a view to reducing complications related to the absorption of the drug, therapeutic suppression and caregivers' undue exposure to the drug.

DESCRIPTORS: Anemia, Sickle cell; Drug therapy; Mothers; Pediatric nursing.

TERAPIA MEDICAMENTOSA NO DOMICÍLIO: EXPERIÊNCIAS DE MÃES DE CRIANÇAS E ADOLESCENTES COM ANEMIA FALCIFORME

RESUMO: Objetivo: descrever as experiências de mães de crianças e adolescentes com anemia falciforme acerca da terapia medicamentosa no domicílio. **Método:** estudo descritivo, com análise qualitativa dos dados, realizado em setembro de 2016. Foram entrevistadas oito mães de crianças e adolescentes, em tratamento para doença falciforme, em Unidade de Internação e Ambulatório de Pediatria de um hospital terciário da capital paulista. Os dados foram organizados, codificados e apresentados em categorias, conforme procedimentos preconizados para análise de conteúdo. **Resultados:** as mães apresentaram desconhecimento acerca dos cuidados durante a administração dos medicamentos no domicílio, bem como de eventuais efeitos adversos, mecanismo de ação e benefícios das medicações utilizadas. **Conclusão:** confirmou-se a necessidade da atuação do enfermeiro na orientação das mães para a administração segura e correta dos fármacos no domicílio, a fim de reduzir complicações relacionadas com absorção do medicamento, supressão terapêutica e exposição indevida dos cuidadores à droga.

DESCRIPTORIOS: Anemia falciforme; Tratamento farmacológico; Mães; Enfermagem pediátrica.

TERAPIA MEDICAMENTOSA EN DOMICILIO: EXPERIENCIAS DE MADRES DE NIÑOS Y ADOLESCENTES CON ANEMIA DE CÉLULAS FALCIFORMES

RESUMEN: Objetivo: describir las experiencias de madres de niños y adolescentes con anemia de células falciformes acerca de la terapia medicamentosa en domicilio. **Método:** estudio descriptivo, con análisis cualitativo de los datos, desarrollado en septiembre del 2016. Fueron entrevistadas ocho madres de niños y adolescentes sometidos a tratamiento para enfermedad de células falciformes en Unidad de Internación y Ambulatorio de Pediatría de un hospital terciario de la capital del estado de São Paulo. Los datos fueron organizados, codificados y presentados en categorías, según los procedimientos recomendados para análisis de contenido. **Resultados:** las madres mostraron desconocimiento acerca de los cuidados durante la administración de los medicamentos en domicilio, y también de eventuales efectos adversos, mecanismo de acción y beneficios de las medicaciones utilizadas. **Conclusión:** se confirmó la necesidad de actuación del enfermero en la orientación de las madres para la administración segura y correcta de los fármacos en domicilio, con objeto de reducir complicaciones relacionadas a la absorción del medicamento, supresión terapéutica y exposición indebida de los cuidadores a la droga.

DESCRIPTORIOS: Anemia de células falciformes; Tratamiento farmacológico; Madres; Enfermería pediátrica.

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● INTRODUCTION

Onco-hematological disorders are pathologies that alter the normal functions of the elements present in the blood, as well as the factors responsible for hemostasis. In childhood, these disorders are mainly anemia, leukocytosis and bleeding, and occur secondary to infections, inflammatory, nutritional and malignant diseases, the latter being less frequent⁽¹⁾.

Sickle cell disease (SCD), a group of hemoglobinopathies that result from the combination of anomalous hemoglobin (S) and other altered hemoglobins, is one of the most incident hematological diseases in the pediatric population⁽¹⁻²⁾.

Sickle cell anemia (SCA) is the most common and severe form of SCD⁽²⁾. In Brazil, about 3,500 cases of SCA are diagnosed per year, which reveals the significant prevalence and clinical importance of the disease, making it a public health problem⁽³⁾. The morbidity and mortality rates of this anemia are high on the African and South Asian continents, while mortality has dropped drastically in developed countries (less than 2% up to 15 years of age)⁽⁴⁾.

Specific treatments for SCA are still non-existent, which justifies the relevance of early diagnosis to improve the child's survival and quality of life^(2,5). After the disease has been diagnosed, treatment protocols established by Brazilian or international cooperative groups are initiated, essentially based on the combination of different continuous prescription drugs and supportive treatment⁽³⁾. Due to the intensity of the treatment, it is important that it occurs at a specialized center for the treatment of hematological diseases⁽⁴⁻⁶⁾.

In Brazil, the diagnosis can be obtained at birth by performing the heel lance, as part of the Health Department's Neonatal Screening Program⁽⁷⁾. After it has been identified that the child has SCD, symptom control will start and continue across the lifetime. Parents will be advised on the importance of maintaining the infant's hydration and nutrition, as well as the need to prevent infections, which can be done during immunization programs or through other prophylactic measures⁽⁵⁾.

In addition to all this care, the child will receive medications to control the disease and the most prevalent symptoms. The effective therapeutic options include treatment with Hydroxyurea (HU) and Hematopoietic Stem Cell Transplantation (HSCT)⁽⁶⁻⁸⁾, the latter being the only curative therapy.

Patients and caregivers may present questions related to drug therapy that may lead to problems such as: loss of doses, incorrect doses or non-administration of prescribed drugs, incorrect time and other complications related to drug absorption and effect, as well as issues involving safe management⁽⁹⁾. Thus, this study aimed to describe the experiences of mothers of children and adolescents with SCA concerning home-based drug therapy.

● METHOD

Descriptive study with qualitative analysis of the data, carried out at the Pediatric Inpatient and Outpatient Service of a teaching hospital in the state capital of São Paulo, a referral institution for the treatment of chronic childhood diseases. The researchers invited the following to participate in the study: mothers of children and adolescents under treatment for SCA, who were monitored at the institution and who were receiving medication at home. Mother who presented limitations to understand the theme and the research objectives were excluded.

The participants were included after signing and clarifying the information in the Informed Consent Form, formally authorizing their participation and subsequent recording of the data. Eight mothers of children and adolescents undergoing treatment for SCA in the hospital and outpatient settings participated.

Data were collected through semistructured, audiotaped interviews, conducted during a single meeting at the Pediatric Inpatient or Outpatient Service, according to the mothers' availability, during September 2016. The inclusion of new subjects was suspended when the set of empirical data was sufficient to respond to the research objective and understanding of the research phenomenon⁽¹⁰⁾.

The analysis and data collection processes occurred concomitantly, according to the assumptions and procedures of content analysis. The steps followed were: 1) Preparation phase, which consists of the collection and selection of data suitable for content analysis; 2) Organization phase, which includes the coding and creation of categories through an abstraction process; 3) Communication phase, in which the results are presented in categories that describe the phenomenon studied⁽¹¹⁾.

To illustrate the themes, excerpts from the subjects' discourse were selected, which were represented by the letter "E", followed by a number indicating the order of inclusion in the research.

The study received approval from the Research Ethics Committee of the institution where the data were collected (Protocol 1.638.459/2016), in compliance with the ethical precepts adopted in research involving human beings⁽¹²⁾.

● RESULTS

Eight mothers of children with SCA participated, aged between 24 and 56 years old. The age of the children and adolescents ranged from three to 16 years, and the time of diagnosis of SCA from two to 14 years. Six of the index cases were diagnosed in the first year of life.

Six interviewees did not have a paid job (75%) and took care of the child and their home. One of the participants presented had not finished higher education and the others had not finished secondary education.

After the analysis, the data were grouped into two broad categories: Home-based drug administration routine and Determinants of compliance with home-based drug therapy.

Home-based drug administration routine

The children and adolescents whose mothers participated in the study used drugs established in Brazilian and international protocols for the control of SCA, such as folic acid and other B Complex vitamins, Hydroxyurea (HU) and Iron Chelators. The mothers reported administering the medication daily, at the same time, as observed in the following statements:

Well, the Hydroxyurea I give in the morning, around nine or ten o'clock in the morning, diluted. B Complex and folic acid I give in the afternoon. (E1)

The participants reported that their children received the medications on days set by the doctor, sometimes alternately throughout the week, especially the HU:

So, Hydroxyurea, he [child] takes two capsules a day on Monday and two on Friday, and the rest of the weekdays he takes one. (E2)

Two participants mentioned a more flexible routine schedule in medication administration:

So, the doctor asked to give it until noon, so no matter what time you give it, but until noon. So whenever he [the child] gets up, I give it around eight, nine o'clock. I give Hydroxyurea and the other medicines together. (E2)

Mothers reported administering HU at night, which was observed as a consequence not of their knowledge of the recommendations about the period when the therapeutic effects of the drug could

be minimized, but rather the fact that this time is more convenient to their routines, as other treatment medications were already routinely administered at night, as noted in the following statement:

The times are always the same, she always takes it in the afternoon and evening. Because she [the child] goes to school in the morning, at night it gets calmer to take it, after she gets home. (E8)

In this category, the maternal reports on HU administration stand out. All children and adolescents used it, being the main medication recommended by the current therapeutic protocols for the treatment of AF. Regarding the guidelines for its administration, the mothers stated that they only received instructions on the dosage, and not specifically on the necessary precautions for the manipulation of the drug, as described in the following section:

I give it in the syringe, I put 5 ml of water. I open [the capsule] to mix it with the water and then I give it to her. I put the water in a little glass, take the syringe, pull the water and see if it is the right quantity, then I put the medicine inside and then put it in her mouth. (E5)

Only one participant reported the need to use gloves to prepare the medication and correctly dispose of leftovers. This information was not provided accurately and not by a health professional, but by a known person:

There are people I know who have told me to wear gloves, even for her sake [child], and if possible use that thing on my face [surgical mask], because they say it's strong. They said to throw it in the trash, not leave it near other children who do not take it. (E5)

Determinants of compliance with home-based drug therapy

Overall, the participants presented limited knowledge regarding sickle cell disease, the care needed during home-based drug preparation and administration and the adverse effects. One can identify this lack of information about the disease in the following statement:

What the doctor gave me was that it was going to help her [child] in the Sickle Cell Anemia. That if she took it right, it would help a lot. But what each [medicine] serves for, I do not know, only "Bezetacil" [Benzetacil®], which serves not to have inflammation and not get the flu, those things, right? (E8)

Two interviewees, when questioned about the indications of the drugs the children used, denied knowledge about the drugs: *No, I cannot even imagine (E2).*

One of them even said that she did not look for information about it: *No, I never took the package insert to read. (E1)*

Even when the participants showed to be better instructed about the purpose of the medications, important misconceptions were observed in their reports, as in the following testimony:

So, I think folic acid is for sickle cell anemia. B Complex, I think it's for immunity, it's vitamin. Hydroxyurea, which I have already read in the package inserts, is used to avoid painful crises and also helps in the drop in hemoglobin, and is an iron chelator, so it helps to eliminate the iron. (E6)

Mothers were unaware of the therapeutic and adverse effects of their children's usual drugs. This fact may compromise the therapy prescribed in the control of the disease, mainly in the prevention of common problems in SCA, due to vaso-occlusive phenomena.

One of the participants had superficial knowledge on the action mechanism of the drugs and their adverse effects, for having participated in a lecture on this theme at another hospital institution:

So, because I had a lecture there at the hospital, before he [child] started taking (HU). And I've seen the risks, the favors [benefits] are greater than the risk. Then I started giving it to him correctly, the way the doctor explained. (E6)

One of the interviewees said that the most difficult thing in treatment is dealing with the disease. According to her, if there is a “remedy” to treat it, her role is to administer it:

No, it was not that difficult [drug therapy]. Because what is difficult is to see them sick, so if the medicine helps, we take the medicine and give it. Because we think it will help, that he will improve and that is what happens. (E6)

It is observed, in the above discourse, that the interviewee showed confidence in the medication and its purpose. According to her, it could help the child, despite ignoring that the therapeutic benefits can coexist with adverse effects.

Although they did not fully understand the aims of the drug (HU), some mothers recognized its benefits and improvement in the children and adolescents’ general condition:

That Hydroxy urea that is more complicated, I do not know what it is for, but I know it helps a lot. (E7)

After I saw that she [child] started taking (HU), she started to get well. Me seeing her well, I feel well too. (E5)

One of the mothers pointed out that the advantages of using the drug became even more evident when the child’s therapy was interrupted due to a lack of medication at the health service:

It really helps, because those days the medication was missing at the [health] service. And he spent almost a month without taking it. And they [children with SCA] cannot be left without taking this medicine. (E6)

At the beginning of the treatment, the lack of knowledge on the disease and treatment were barriers to home-based medication administration, as follows:

It was difficult at first because I did not even know what it was [disease]. I was very young when I discovered what he [child] had, he was my first child. It was difficult, because I did not know it, I had no idea of things. I had to learn on the go. I’ve gotten used to it today. (E3)

The lack of clarification on the effects of the medications generated fear and doubts as to the correct way of administering them, as expressed in the testimony below:

It was a bit difficult [to administer the medications at home], to see her [child] so “little” taking medicine. Because when I went to buy it at the pharmacy, I asked the woman, “Do you have Hydroxyurea?” She [pharmacist]: “Yes, is it you who is going to take it?” I said, “No, it’s my daughter.” She: “Wow, so little taking Hydroxyurea, such a strong medicine!” Then I became more scared. (E5)

● DISCUSSION

The two categories found demonstrated the misconceptions regarding the administration of medicines at home. Due to the lack of guidelines, five mothers reported administering them at the times most convenient for themselves or according to the routine of the child, not necessarily at the prescribed time or at the time of day that minimized or enhanced the therapeutic and/or adverse effects of the drugs.

Complex B vitamins and folic acid may be given together or separately from meals, depending on the gastric sensitivity of the child or adolescent. The administration of HU should take place preferably at night, in order to minimize gastric discomfort, a commonly observed adverse effect^(8,13).

A study⁽¹³⁾ on compliance with HU showed that the more complex the prescribed regimens, the greater the chances of forgetting doses, which is even more likely if schedules vary during the week.

Another important factor, present in the literature and with implications for compliance with this medication, concerns the lack of communication between professionals and caregivers⁽⁸⁾. In this study, it was noticed that the medication administration was incorporated into the routine of the participants and their children, without considering the properties of the drugs in question.

HU is one of the most commonly used medications to minimize complications related to sickle cell disease. It is a chemotherapeutic drug whose action mechanism is to increase the production of Fetal Hemoglobin (HbF) and reduce the vasoconstriction stimuli. This drug offers several therapeutic benefits to children and adolescents with SCD, however, it can cause serious adverse effects, mainly due to its prolonged use⁽⁵⁻⁶⁾.

Studies^(8,13-14) demonstrate the prevalence of gastrointestinal discomfort, hyperpigmentation of the skin, renal and hepatic toxicity. In addition to these effects, HU is a myelosuppressive drug, that is, it causes a decrease in the activity of the bone marrow, leading to a drop in the concentration of red, white and platelet cells. This effect is therapeutic for the child who has SCD, but not for the caregiver who has contact with the drug⁽¹³⁾.

Therefore, it is recommended to use procedure gloves and a mask to avoid contact of the substance with the skin and mucous membranes, besides the correct disposal of leftovers of the medicine, which has to be wrapped in a plastic bag and disposed of separately in a place of difficult access for children and animals^(8,14).

In this study, however, almost all caregivers did not use any type of personal protective equipment (PPE). Only one interviewee wore gloves to administer the drug, but she wrongly reported that she used them for the child's sake and not for her own protection, which demonstrates the lack of knowledge and instruction about precautions for HU manipulation.

The literature points to the need to instruct parents about the effects of cytotoxic drugs on the body of healthy people⁽¹³⁾. It is imperative that health professionals, including nurses, advise caregivers on safe practices in the handling of drugs such as HU, highlighting their harmful effects and informing them about alternatives for the manipulation, administration and disposal of these substances in the home context⁽⁸⁾.

Regarding the limitations observed in the reports regarding the acquisition of information and the difficulty to obtain the main drug used in the treatment, it is important to highlight the relevance of the caregivers' profile and its relation with greater knowledge and compliance with home-based drug therapy, identified both in this study and in two other international studies^(8,13).

Results from another research⁽¹⁵⁾ pointed out that the educational level and the demographic characteristics of primary caregivers did not influence treatment compliance. Nevertheless, a Brazilian study⁽¹⁶⁾ showed that demographic profile, level of education and socioeconomic aspects exert influence on treatment compliance. This controversy in the literature may derive from the socioeconomic and educational disparities between the different scenarios in which both studies were developed.

Six participants in the study had a low educational level and low income. Limitations in the level of education may aggravate the understanding of the therapeutic and adverse effects and aspects related to the correct disposal of drugs in a non-hospital context.

The socioeconomic aspects figures as an important barrier for good practices related to the administration of cytotoxic drugs, such as HU, at home. The necessary precautions, such as the acquisition of PPE for home use, were not feasible for the families, considering the difficulties to obtain even the drugs in the public health service.

Children with sickle cell disease are hospitalized about five times a year and need regular follow-up with a hematologist⁽¹⁷⁾. This chronic pathology requires lifelong care⁽¹⁸⁾, which changes the family dynamics and requires adaptation to this new reality. The maternal figure, predominant among the study participants, undergoes most of the consequences related to care for the child, as she gives up participating in the family income to exercise the role of full-time caregiver⁽¹⁹⁾.

In the reports, it could be identified that the caregiver had a positive perception of the drug therapy, especially with regard to HU. The ignorance seemed to turn the administration of the drug at home a routine activity, so they did not question any risks related to its prolonged use. In an American study⁽¹⁸⁾, the caregivers' resistance to the therapy with this drug was identified, due to its harmful effects, namely: gastrointestinal alterations, myelosuppression, rashes, teratogenic and carcinogenic potential.

Due to the above-mentioned effects, some parents refused to administer HU to their children, compromising the treatment compliance, unlike the caregivers interviewed in this study, who recognized more benefits than harmful effects of the drugs in the body, possibly because they were unaware and therefore, did not question the negative factors of the therapy in the long term.

Without (sufficient) basic information, these caregivers may make mistakes during the drug administration and seek the health service late, as they do not know the properties of the drugs, nor the signs and symptoms suggesting that the therapy is not evolving as expected.

This lack of knowledge indicates a failure in the health professionals' instruction, with emphasis on the nurse, who maintains greater contact with caregivers and develops educational and informational activities as part of nursing attributions⁽⁶⁾. According to a study about the treatment compliance of pediatric patients with SCA, deficient communication between caregivers and professionals is one of the factors that most favor drug-related errors and lack of compliance with home-based therapy⁽¹⁸⁾.

One of the interviewees reported having read in the package insert that HU is a medicine that helps to eliminate iron. One of the adverse effects of the drug is exactly the opposite though, that is, to delay iron excretion⁽¹³⁾. This misconception demonstrates the need to advise the participants as, even when searching for information by their own means, they face difficulties to interpret the contents expressed in package inserts or other sources of information.

Activities such as these are fundamental and should be accessible to all caregivers, but preferably at the institution where the monitoring takes place as, thus, the guidelines will be in agreement with the treatment protocol adopted at the treatment service, in addition to following the characteristics of the population attended there.

The impact of the information regarding the drug and its benefits is directly proportional to the compliance, i.e. if the subject is unaware of the therapeutic purpose and the positive aspects of the drug, he will not use it correctly⁽¹⁶⁻¹⁸⁾. In the case of medications such as HU, this fact is directly related to the benefits of the drug, that is, if its use is conscious and complacent, the chances of painful crises and other complications related to SCA will be lower⁽¹⁵⁾.

In the previously mentioned aspects, the fundamental role of health education is clear, which needs to be performed by the nurse, both during lectures and dynamics and through other instructional resources, always in accordance with the family members' level of understanding.

This study comes with two limitations: it was conducted at only one health institution and it only addressed the perspective of mothers.

● CONCLUSION

The results of this study describe the experiences of mothers of children and adolescents with SCA regarding home-based drug therapy and alert to the lack of knowledge of this clientele concerning the purpose of the medications used during the treatment of the disease. They also reveal limitations with regard to care in the safe administration of the drugs, such as standardization of dosages and administration routine, and especially regarding the precautions related to the exposure to and disposal of the main drug in the treatment protocol (HU).

Home-based drug therapy for children and adolescents with SCD is essential for the continuity of care and for a better prognosis. Therefore, it is fundamental that caregivers be prepared and guided by the professionals to carry out the correct administration of the drugs, minimizing errors and avoiding consequent risks for the child and to themselves.

This is a pioneering study in the Brazilian literature and suggests that future research be extended to other subjects, such as fathers, adolescents (who already have autonomy for self-care), and professionals

who take care of this clientele. The relevance of the use of other methodological approaches in the study of this subject and of aspects related to sickle cell disease and its treatment is highlighted.

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