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ORIGINAL ARTICLE

HEALTH EDUCATION STRATEGY WITH FAMILY MEMBERS OF CHILDREN IN CONTINUOUS MEDICATION

ESTRATÉGIA DE EDUCAÇÃO EM SAÚDE COM FAMILIARES DE CRIANÇAS EM USO CONTÍNUO DE MEDICAMENTOS

ESTRATEGIA DE EDUCACIÓN PARA LA SALUD CON LOS FAMILIARES DE LOS NIÑOS EN LA MEDICACIÓN CONTINUA

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ABSTRACT

Objective: to identify the doubts of relatives of Children with Special Health Care Needs (CRIANES) related to the continued use of drugs. **Method:** a descriptive study, with a qualitative approach, developed in a university hospital in Rio de Janeiro/RJ, Brazil with 13 relatives of Children with Special Health Care Needs (CRIANES) with medicine care demand. It was operationalized from the semi-structured interview and conversation wheel. After collecting data, the speeches of the family members were fully transcribed and analyzed using content analysis. **Results:** the family members brought up several questions related to the use of drugs, ranging from their preparation and the effect on the child's body to its proper preparation. The dialogic form of the conversation wheel has confirmed that this is where everybody teaches and learns. **Conclusion:** the conversation wheel is an important strategy for preparing the relatives of CRIANES with medical care demand for their hospital discharge. **Descriptors:** Pediatric Nursing; Family; Child; Health Education.

RESUMO

Objetivo: identificar as dúvidas dos familiares de Crianças com Necessidades Especiais de Saúde (CRIANES) relacionadas ao uso contínuo de medicamentos. **Método:** estudo descritivo, com abordagem qualitativa, desenvolvido em um Hospital Universitário no Rio de Janeiro/RJ, Brasil com 13 familiares de Crianças com Necessidades Especiais de Saúde (CRIANES) com demanda de cuidado medicamentoso. Operacionalizada a partir da entrevista semiestruturada e da roda de conversa. Após a coleta de dados, as falas dos familiares foram transcritas na íntegra e os dados analisados por meio da análise de conteúdo. **Resultados:** os familiares trouxeram à tona diversas dúvidas relacionadas ao uso de medicamentos, que variaram desde seu preparo e o efeito no organismo da criança até seu preparo adequado. A forma dialógica da roda de conversa confirmou que este é o local onde todos ensinam e todos aprendem. **Conclusão:** a roda de conversa é importante estratégia para o preparo de alta dos familiares de CRIANES com demanda de cuidado medicamentoso. **Descritores:** Enfermagem Pediátrica, Família, Criança, Educação em Saúde.

RESUMEN

Objetivo: identificar las dudas de los familiares de los Niños con Necesidades Especiales de Salud (CRIANES) en relación con el uso continuado de medicamentos. **Método:** estudio descriptivo con un enfoque cualitativo, desarrollado en un hospital universitario de Río de Janeiro/RJ, Brasil con 13 familiares de niños con necesidades especiales de salud (CRIANES) con la demanda de atención de remedios. Desarrollado a partir de la entrevista semi-estructurada y ruedas de conversación. Después de la recogida de datos, los discursos de los familiares fueron transcritos y analizados mediante análisis de contenido. **Resultados:** los familiares trajeron varias preguntas relacionadas con el uso de drogas, que van desde su preparación y el efecto sobre el cuerpo del niño a su preparación adecuada. La forma dialógica de la rueda de conversación ha confirmado que este es el lugar donde todos enseñan y todos aprenden. **Conclusión:** la rueda de conversación es una estrategia importante para la preparación de alta de los familiares de CRIANES con la demanda de atención de remedios. **Descriptor:** Enfermería Pediátrica; Familia; Niño; Educación en Salud.

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INTRODUCTION

In the routine care of hospitalized children, it is possible to observe that some of them have special health needs that remain after hospital discharge. This continued treatment requires care to be performed at home by their families, who need to have some technical knowledge.

In recent decades, there have been important changes in the epidemiological profile of Brazilian children. In the past, vaccine-preventable diseases were the main causes of morbidity and mortality. Currently, perinatal diseases draw a new trend for that picture. The advancement of technology and the evolution of scientific knowledge resulted in a longer life of medically fragile children, and the incorporation of new technologies in the recovery of childhood diseases by congenital and acquired causes provided a significant increase in critical children that survived with special health care needs.^{1,2}

The technological advent led to the emergence of a group of children who depend on technology and health care, known in the literature as Children with Special Health Care Needs (CSHCN), and Brazil, as *Crianças com Necessidades Especiais de Saúde* (CRIANES).^{2,3}

The CRIANES are defined as children with special health conditions who require continuous care, whether temporary or permanent. Those needs revolve around care demands classified into four groups: development, technological, medical and modified usual care.^{2,4}

A study that aimed to analyze the care demands of CRIANES after hospital discharge showed the lack of support by health services and the society, in addition to the total lack of monitoring or support for the families of those children.⁵

When CRIANES are discharged, their families face the need for care of different kinds, which are necessary for the survival of the child outside the hospital. Among those cares, this study addressed the drug one because, in the case of children, the doses are often prescribed in small volumes, and family members may have questions about their preparation and administration, which compromises the child's treatment.

The literature shows that the process of discharge of the child involves the performance of the professional to the continuity and comprehensiveness of care. Currently, one preconizes early discharge, because reducing the time of hospitalization decreases the negative effects of separation

between children and their families. Therefore, sometimes the children are released from the hospital before completing the treatment of illness and rehabilitation of health. In this context, the family is responsible for continuing the care outside the hospital until the complete recovery of health.^{6,7}

Given that new reality, the exchange of knowledge between health staff and family is necessary for the discharge, and should begin preferably at the time the child enters the hospitalization process.^{5,7} In this sense, it is necessary, during hospitalization, to perform activities for health education, guidance and preparation of accompanying family members who will be in charge of taking care of children at home.

Health education is concerned with the relationship among knowledge and the health-disease processes of individuals and the community, being possible to produce and share knowledge shared, resulting in transformation in the understanding of the health-disease process.⁸

Before the implementation of health education practices, especially in the case of homecare-dependent children, it is necessary to listen to the family, meet their needs and concerns, in order to think of strategies to give the best for the family and the child.

Based on the assumption of the need to hear the participants so that the health education process is dialogical, this research has the theoretical conceptions developed by Paulo Freire.^{9,10}

The education model proposed by Freire breaks with the characteristic vertical schemes of banking education. In his view, dialogue is beyond the act of depositing ideas of a subject in the other. The problem-based education is a way to practice freedom when breaking the verticality and proposing, through dialogue, a cross-sectional and dialogical relationship between the subjects. It has an essentially reflexive character and implies constant critical question of reality.^{9,10}

As health education strategy, developed in this study, with the relatives of CRIANES, one opted for the conversation wheel, and, thus, supported by the assumptions of Freire's education as a liberating education, since, in the wheel, everybody teaches and learns, as in the Culture Circles.¹⁰

Based on the above, one defined the following subject of study: health education along with the accompanying relatives to the hospital discharge of children with special

health needs in continuous use of medication. The objectives were so determined:

- To identify the doubts of relatives of Children with Special Needs Family Health (CRIANES) related to the continued use of drugs.
- To analyze the possibilities of continued drug use as a health education strategy along with those family members.

METHOD

Descriptive study, with a qualitative approach, developed in 11 pediatric inpatient unit of a university hospital located in the state of Rio de Janeiro/RJ. The participants were 13 family caregivers of children with special health care needs in continuous use of medication at home, hospitalized during the data collection period. All participants were female and eight were mothers, two, grandparents, two, sisters and one, aunt.

The inclusion criteria were relative aged over 18 years; with participation in home care of children with special health care needs in continuous use of medication at home. The exclusion criteria were relatives caregivers of children in need of full-time attention, preventing them to participate in the research.

The number of participants was set in the course of fieldwork, where, through the organization of interviews, one sought to identify the data saturation, that is, the existence of redundancy and repetition of ideas, behavior patterns, and visions of world.¹²

Data collection took place from August to November 2013. It was operationalized from the semi-structured interview and the wheel itself, with open and closed questions. Closed questions aimed at identifying the characteristics of the subjects, and open, the family doubts. This step supported the preparation of the material for the realization of the conversation wheel, as a health education proposal along with them.

In the conversation wheel, the concerns raised were problematized, allowing participants to realize their needs and, together, develop strategies for possible solutions to their daily problems. The caregivers were able to speak, ask questions, show how they performed home care, and interact with the other participants of the wheel and with the researchers, in addition to acquiring technical and practical knowledge, and exchange experiences.

During the research, there were five conversation wheels. They occurred at the

sector itself, in a private room and away from other patients and caregivers. The first wheel conversation lasted 35 minutes, with the participation of two caregivers, being one mother and one aunt. One mother and one sister attended the second one, which lasted 30 minutes. Three caregivers - one mother, one grandmother and one sister - attended the third one, which lasted 1 hour and 20 minutes. Two mothers attended the fourth one, which lasted 53 minutes. The fifth one lasted 42 minutes, with the participation of four companions - three mothers and one grandmother.

For the full and accurate record of the statements of participants, interviews and conversation wheels were recorded with the help of an mp3 player, with their prior authorization.

After collecting data, the speeches of the family were fully transcribed and analyzed by content analysis technique¹³, classified from colors, in which speeches with the same sense were colored with the same color. After coloring the speeches, the data were aggregated into tables, thus leading to the specificity of the theme.

The study was approved by the Research Ethics Committee of the institution where it was held (CAAE: 17770613.8.0000.5243/Opinion 330,164) and complied with all aspects contained in the CNS Resolution 466/12. The anonymity of participants was maintained all the time. Therefore, fictitious code names were used to identify them - by names of characters from child movies.

RESULTS

With the data analysis process, two categories emerged: doubts of relatives of CRIANES regarding home care related to the continued use of medication, and the conversation wheel as health education strategy along with the family to prepare the discharge of CRIANES in continuous medication.

♦ Doubts of relatives of CRIANES regarding home care related to the continued use of medication

During the interviews and the conversation wheels, relatives raised several questions related to the use of medicine, ranging from the effect of it in the child's body to its proper storage at home.

Participants indicated that they feel concerned about the tachycardia caused by the effect of berotec®, a bronchodilator commonly used to nebulization. As a result of

tachycardia caused by the medicine, some relatives do not administer the prescribed dose, for they fear the child may suffer a heart attack. Those doubts are indicative of the lack of knowledge of the expected effects of the drug:

I have questions regarding the berotec®, I get scared because some say that the berotec® can lead to a heart attack, if you give one more drop [...] When I give berotec®, I keep looking to see if the little heart of hers will get too fast, if it does, I'll stop. (Tiana)

When I nebulise him with berotec®, I feel his heart gets too accelerated. (Megara)

Other concerns raised by family members were effects such as agitation and changes in sleep patterns caused by anticonvulsants, antiepileptic, anxiolytics and drugs to treat psychoses. They report that the medication used to cause sleepiness, but it does not anymore, causing them to speculate about why children stay awake:

Sometimes she stays awake one day to the next, let's assume she woke up this morning then she goes up tomorrow morning without sleeping. Little eyes wide open. It may be the effect of medications (topiramate, lamotrigine, frisium® and phenytoin)? (Pocahontas)

I'm finding that the risperidone she used to take, she was asleep in no time, now she's taking a little longer. I do not know if this is little amount, or if it's taking longer to make her sleep. She used to sleep, but now, it has no effect, she gets angry, super agitated. (Mulan)

In some cases, when family members feel uncertain about the effectiveness of drugs, they chose to replace the prescribed one by other not prescribed by the doctor:

She only takes neuleptil. I give it myself, only one day I gave it and she did not sleep, was awake day and night. Then her mother said: mom, let's take a clonazepam! Then I got scared and said: better not give it. My daughter said: we have to give a band, otherwise this girl will not sleep, will be stressed and stress us too. So I gave it and she slept. (Bella)

There were doubts and concerns about the dosage of medicines. One family member highlighted insulin, reporting she did not know the possible consequences of administering a dose higher than the one prescribed:

I have a diabetic son [...] if we, for example, give a measure, even for a millimeter, more of insulin, can it cause a problem? A reaction? Is it wrong? We have to pay more attention to insulin? (Tiana)

On the other hand, some family members revealed they decrease the prescribed dose

because they believe that the indicated dose may cause complications in the child's body:

The doctor prescribed eight drops of berotec®, isn't it too much? I do not give eight, I give three drops, because I've never seen anyone taking eight drops, I've seen five, six. (Cinderella)

It is noticeable the difficulty that family members present in the preparation of the drug at home. They said that, when preparing the drug, they have doubts regarding the material used to prepare or apply the medicine, such as syringes:

When we put the medication in the syringe, and air enters the syringe, then we take the air out, sometimes we end up throwing a little of the diluted drug away. If I take a little, won't the medication go too? [...] I am afraid to put more units in the syringe, for example, there are 10 units, and I put more. I confuse these insulin syringes a lot. (Tiana)

Family members said they have doubts, while preparing the medication, regarding the manipulation of the drug itself, of how to divide the tablet:

Sometimes we can't break divide the tablet, is very choosy, I've never divided into perfect halves, is there a problem giving a little more or a little less than the half? It never gets the same, sometimes I have to take another part, of another tablet, to increase. (White)

It's difficult to break the tablet in the middle, it's never in the middle, in the very middle of it. Then my mother picks up the knife, and stands there looking at (the pill, trying to measure the middle). (Jasmim)

Some family members reported that, in the preparation of the medication, they have questions regarding dilution, as they do not know the right amount of water to dilute the medication; they think that, when diluting medication, it loses its effect:

If I dilute the tablet in more quantity of water, won't it get weaker? (Jasmim)

During the conversation wheel, when the subject was the storage of the medication at home, family members reported what they did at home, and, although they thought they were storing it right, the storage was not adequate:

I keep insulin in the refrigerator, at the door. (Rapunzel)

Can we put medicine that should be stored in the refrigerator at the door? If you leave on the shelf above the vegetable drawer, won't it freeze? (Megara)

Another situation that drew attention during the conversation wheel was the non-adherence to the prescribed schedule of medication. Family members reported not

following the prescribed times, demonstrating they often do not consider the time regularity important:

I do not always follow the right time. Sometimes I give at the right time, sometimes I forget to give. When the time is midnight, I never wake up to give at that time. Then I move to the time I can. The doctor prescribes a bad schedule, I always change. (Aurora)

After exposing the doubts of family members who care for CRIANES in continuous use of medications, we will present the results of the conversation wheel as education strategy along with the family in order to work those doubts.

♦ The conversation wheel as health education strategy along with the family to prepare the discharge of CRIANES in continuous medication

The family members showed they understood the issues addressed in the conversation wheel. It was noticeable through the speeches that, after the wheel, they will try to suit the content learned to their daily lives.

With respect to preparation of the medication, the family members said they will incorporate the ideas and techniques discussed in the conversation wheel, such as tablet dilution in the syringe, use of tablet cutter to facilitate its division and better understanding of the insulin syringe graduation:

It's because I didn't know it (to dilute drug directly in the syringe), now here I have learned, and, at home, I will do it this way (in the syringe). It's also more hygienic, the syringe is already cleaner, I only have to put some water and shake it, so it (tablet) melts [...] With the tablets cutter, it is much more practical, I will waste less medication. (White)

We learn it in a half-hour talk, less than an hour, I learned, right?! Now I had some questions answered regarding those insulin dosages in the syringe, got it? (Tiana)

Also in relation to changing habits at home, the family members said they will change their behavior in relation to the storage of the drug, because, through the wheel, they realized they were doing it inappropriately:

Now the worse is what's in the cooler (insulin). Because I get it there in the unit, then I put everything inside the Styrofoam box, inside the refrigerator. But I'll take it (insulin) out of the Styrofoam box. (Fiona)

The conversation wheel enabled the family members to get to conclusions after they had their questions about drug dosage answered:

I got it. I know the medicine won't get weak. (Jasmin)

It's good to learn, for you to know, right? Same thing with the dosage, sometimes we think it's better, but we end up complicating the child's situation. (Bella)

The speeches of the family members who participated in the conversation wheel confirm that the wheel is a place where everyone teaches and everyone learns. During the conversation wheel, they exchanged experiences about the care performed daily, in addition, they felt more comfortable with the way the conversation wheel happens:

I think this way good, to sit down to talk, everything was well explained, never participated and enjoyed it. With the mothers talking together create doubts in us, together is better than individual. Even if saying there is no doubt, in the middle of other people always talking, doubts arise. (Cinderella)

I found it interesting, right?! I learned more, I liked the strategy of listening to other mothers, I found interesting. (Merida)

I liked it, it's good when everybody is reunited. Each one asking questions and learning from each other. It's good, right?! Always sitting to ask questions. It was valid. (Aurora)

I had a lot of doubt, a lot I did not know. It was easier this way of talking. [...] it got better explained we understand more. [...] It was good! It was all cleared up. (Fiona)

From the relatives' statements, it is possible to say they had their doubts answered during the health education strategy proposed by the research:

After the wheel, it was clarified. I got to understand it better, right, and ask questions about the drugs. (Pocahontas)

For me, it was great [...] I liked it, it answered the questions I had. For me it was a very good explanation. (Megara)

Although family members show they had no more doubts regarding what they had proposed in interviews before the conversation wheel, one can see that if a situation different from the one mentioned in the wheel appears, they may have new doubts:

I have to learn even more, a little bit more (Jasmine).

No (doubts). If there are other medicines, then ... (White)

DISCUSSION

The data showed that the relatives of CRIANES in continuous drug use have questions related to the effects of drugs on the child's body. Such fact highlights the need for instrumentation, because they need to deal

with the adverse effects that interfere with the implementation of home care.¹⁴

When family members, caregivers, do not understand the effects of drugs, there are situations they choose to replace the prescribed drug by other not prescribed by the doctor. The replacement and administration of non-prescription drugs configures as a practice of self-medication.

The most common practice of self-medication include the acquisition of nonprescription medicines, spare reuse of medicines from previous treatments, the use of old prescriptions and sharing of medicines used by other members of the family or social circle. Studies highlight that the irrational use in children and adolescents is still a real and frequent practice in our daily lives.¹⁵⁻¹⁶

It is noteworthy that self-medication may be due to deficiency of knowledge of the family members, since the results of this research showed lack of information regarding the effects of the drug, its administration and proper storage. These data corroborate a study conducted in 2010, which showed that there are people responsible for the care of children who do not have adequate or sufficient knowledge about the correct use of medicines at home. That situation may be one of the reasons why many parents do not comply with appropriate treatment with their children, preventing it from being effective.¹⁶

A study conducted in 2011 revealed that 70% of the events classified as preventable medication errors in children related to the drug administration phase, carried out by parents or caregivers. The improvement in communication between health professionals and people responsible for child care is important and necessary for the prevention of medication errors.^{17,18}

Given this reality, nurses need to seek resources to equip the family, so that, when implementing the use of continuous medications, they are able to correctly read and interpret the doctor's prescription, in addition to maintaining a rigorous dosage to prevent recurrent hospitalizations. In this regard, during the discharge process, the family should be prepared to provide care to the child at home.⁵

The research showed that the use of educational practices that promote dialogue between the professional and the family member responsible for home care, such as the conversation wheel, in addition to knowing the doubts and difficulties when at home, can minimize and likely prevent that medication errors happen.

Another recurring question among family members participating in the research was regarding the prescribed dose. We emphasize that they need to understand that they should administer the dose, as it is appropriate to the child's need for its therapeutic follow-up. A study conducted in 2011 stressed the importance of proper dosage, as overdose may relate to patient safety and underdose, to problems of treatment inefficiency.¹⁸

The data reveal the unpreparedness of the family members in manipulating the material used for the preparation of medications at home. One of the biggest limitations was when dividing the tablet to administer the prescribed dose. That situation meets with a pharmaceutical study in which the authors concluded that the lack of knowledge of who prepares and administers the drugs is liable for damages in the treatment and may cause health damage. It is necessary to pay attention to the family member when preparing the medication so that they administer the right dose on a regular schedule and do the correct fractionation of medicine.¹⁹

There are few specific formulas for child medication in pediatrics, being common the dilution and redilution of medicines so that their use in children is possible²⁰. Those dilutions require knowledge by the family members, such as mathematical calculations, which they may not have domain. A study proved the difficulty to dilute the drugs, and made it clear that there should be no doubt during their preparation, since there is a high probability of errors to happen²². Therefore, health education with the family must be effective, and clearly, in order to prevent such errors.

Another aspect contemplated in the study was the doubt regarding the proper storage of the drug at home. It is important that family knows how to store the drug, since it directly affects the quality and effectiveness²². Therefore, the family, besides knowing the adverse effects of medication and paying attention to the prescribed dose, should determine the period of validity contained on the box and on the card and be careful with the storage⁵. Moreover, properly storing the medicine, observing the need, or not, for cooling, maintains its stability and ensures completeness during its validity.²²

Another point highlighted by the caregivers meets with another study showing that family members had difficulty in following the prescribed schedules of medications.²⁴ That can occur by forgetting, by relying on

someone else to make the medication because of an inappropriate time.

A study with community health agents identified that the major problems related to drugs found in households involved storage, self-medication, time and incorrect doses. Thus, the authors could conclude that those errors directly relate to lack of understanding and adherence to guidelines exposed to the family.²³

In the conversation wheel, family members could expose their doubts, answered by the researchers, and, from the health education, the relatives began to reflect on the daily care and on the prepared and administered medications. That health education strategy aroused in family members their skills and abilities for a better care, taking into account their experiences, seeking only to improve them.²⁴

One knows that the challenge of caring for a CRIANES at home involves the need for family members to learn practices that not always were part of the family routine. Therefore, health education of those families need to take into account the assistance provided by those caregivers^{25,26}. Moreover, it should happen steadily, because the needs of children and their families can change according to the proposed treatment, as well as for their response to treatment.

Family education not only improves the quality of life of a child who depends on the continuous use of the drug, but also reduces expenses with emergency services, medications and hospitalizations that could be avoided through proper guidance.²⁷

CONCLUSION

The research identified that the relatives responsible for home care of children with special health care needs continuously using medication had doubts regarding the effects on the child's body, medication efficacy, dosage, preparation, administration and drug administration schedule. Feeling at ease to expose day-to-day doubts and difficulties, the relatives accepted the health education carried out through the conversation wheel, directed to answer their questions.

That health education strategy can help professionals prepare the families for the discharge of children with special health needs with medical care demand at home. It is due to its potential to awaken new skills and abilities to better intervention in childcare.

The biggest gain of the study was to show that, despite the positive outcome of the

health education strategy, family members have pointed out that it is necessary that education is constant and permanent, because there will always be new questions, and the health team must be attentive to signs that something is wrong, the only way to prevent errors.

The study is an important tool to assist health professionals in the search for strategies to prepare the families of children with special health needs with medical care demand. The better the discharge preparation process, the less doubts those families will have at home.

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