

EDUCATIVE PROCESS WITH RELATIVES OF CHILDREN WITH SPECIAL HEALTH NEEDS IN THE HOSPITAL-HOME TRANSITION

Meirilane Lima Precce¹ 

Juliana Rezende Montenegro Medeiros de Moraes¹ 

¹Universidade Federal do Rio de Janeiro, Escola de Enfermagem Anna Nery. Rio de Janeiro, Rio de Janeiro, Brasil.

ABSTRACT

Objective: to analyze the dialogical educative process as a strategy to prepare the relatives of children with special health needs in the transition from hospital to home.

Method: qualitative study developed from the Creative Sensitive Method, carried out between February and June 2018 at the Inpatient Unit of a public hospital located in the city of Rio de Janeiro. Family caregivers of nine children with special health needs in transition from hospital to home were included in the study, totaling nine participants. The empirical material was evaluated through the analysis of the French discourse.

Results: the educative process allowed the relatives to unveil demands for technological and medicative care, modified habitual elements, clinically complex care and social demands to be worked on by the nurse in the transition from hospital to home. From the analysis, the following category emerged: The educative process as a strategy to prepare the relatives of children with special health needs in the transition from hospital to home. The dialogue was produced, however, without exhausting the I-You relationship, maintaining the dialogicity in the group and encouraging the exchange between the different realities of the relatives.

Conclusion: the educative dialogic process is an adequate strategy to prepare the relatives of children with special health needs in the hospital-home transition, where the nurses act as coordinators, suggesting a minimum program-related content.

DESCRIPTORS: Pediatric nursing. Caregivers. Health education. Chronic disease. Children with disabilities.

HOW CITED: Precce ML, Moraes JRMM. Educative process with relatives of children with special health needs in the hospital-home transition. *Texto Contexto Enferm* [Internet]. 2020 [cited YEAR MONTH DAY]; 29:e20190075. Available from: <https://doi.org/10.1590/1980-265X-TCE-2019-0075>

PROCESSO EDUCATIVO COM FAMILIARES DE CRIANÇAS COM NECESSIDADES ESPECIAIS DE SAÚDE NA TRANSIÇÃO HOSPITAL-CASA

RESUMO

Objetivo: analisar o processo educativo dialógico como estratégia de preparo dos familiares de crianças com necessidades especiais de saúde na transição do hospital para casa.

Método: estudo qualitativo desenvolvido a partir do Método Criativo Sensível, realizado entre fevereiro e junho de 2018 na Unidade de Pacientes Internos de um hospital público localizado na cidade do Rio de Janeiro. Familiares cuidadores de nove crianças com necessidades especiais de saúde em transição do hospital para casa integraram o estudo, totalizando nove participantes. O material empírico foi avaliado por meio da análise do discurso francesa.

Resultados: o processo educativo permitiu que os familiares desvelassem demandas de cuidados tecnológicas e medicamentosas, habituais modificados, cuidados clinicamente complexos e demandas sociais a serem trabalhados pelo enfermeiro na transição do hospital para a casa. Da análise, emergiu a categoria: o processo educativo como estratégia de preparo dos familiares de crianças com necessidades especiais de saúde na transição do hospital para casa. O diálogo foi produzido, porém, sem esgotar a relação eu-tu, mantendo a dialogicidade no grupo e incentivando o intercâmbio entre as diferentes realidades dos familiares.

Conclusão: o processo educativo dialógico é uma estratégia adequada para preparar os familiares de crianças com necessidades especiais de saúde na transição hospital-casa, no qual os enfermeiros atuam como coordenadores, sugerindo um conteúdo programático mínimo.

DESCRITORES: Enfermagem pediátrica. Cuidadores. Educação em saúde. Doença crônica. Crianças com deficiência.

PROCESO EDUCATIVO CON LOS FAMILIARES DE NIÑOS CON NECESIDADES ESPECIALES EN LA TRANSICIÓN HOSPITAL-CASA

RESUMEN

Objetivo: analizar el proceso educativo dialógico como estrategia de preparación de los familiares de niños con necesidades especiales en la transición del hospital a la casa.

Método: estudio cualitativo desarrollado a partir del Método Creativo Sensible, realizado entre febrero y junio de 2018 en la Unidad de Pacientes Internados de un hospital público situado en la ciudad de Rio de Janeiro. El estudio se realizó con familiares cuidadores de nueve niños con necesidades especiales en transición del hospital hacia la casa, compuesto por el total de 9 participantes. El material empírico se evaluó por medio del análisis de discurso francés.

Resultados: el proceso educativo permitió que los familiares develaran demandas de cuidados, tecnológicas y medicamentosas, cuidados habituales modificados, cuidados clínicamente complejos y demandas sociales que deben ser trabajadas por el enfermero en la transición del hospital hacia la casa. Del análisis, emergió la categoría: el proceso educativo como estrategia de preparación de los familiares de niños con necesidades especiales en la transición del hospital a la casa. El diálogo se produjo, sin embargo, sin agotar la relación yo-tu, manteniendo el carácter dialógico en el grupo e incentivando el intercambio entre las diferentes realidades de los familiares.

Conclusión: el proceso educativo dialógico es una estrategia adecuada para preparar los familiares de niños con necesidades especiales de salud en la transición hospital-casa, en el cual los enfermeros actúan como coordinadores, sugiriendo un contenido programático mínimo.

DESCRITORES: Enfermería pediátrica. Cuidadores. Educación en salud. Enfermedad crónica. Niños con discapacidad.

INTRODUCTION

With the advancement of technology, intensive care has saved lives and generated a new group of children with chronic, physical, developmental and behavioral or emotional conditions that require more care by health services compared to other children. Those are described, in the international literature, as *Children with Special Health Care Needs* (CSHCN)¹ and, in the Brazilian literature, as *Crianças com Necessidades Especiais de Saúde* (CRIANES).²⁻⁴

The United States estimates that 10.2 million children need special health care, relating the demands to learning and attention difficulties (41%), anxiety or depression (29%), behavior problems (28%), difficulty in speech (23%) and social relationship (20%).⁵ In Brazil, however, there are no official rates that characterize this population.⁵

The CSHCN, a relatively new child group in health care, demand services that guarantee their survival and are divided into six groups, according to the typology of their demands, namely: 1) technological: Technology-dependent children for the maintenance of their lives, such as respirators, semi-implantable venous catheters, etc.; 2) medicative: Referring to the continuous use of life-sustaining drugs such as antiretrovirals, neuroleptics, etc.; 3) development: Including developmental-lagging children and those most in need of rehabilitation services; 4) modified habitual elements: Children who need changes in the usual way of taking care, such as bathing, walking and eating; 5) mixed cares: Children who have one or more demands, excluding technological and 6) for clinically complex cares: Which includes all the demands to maintain life.⁶

Due to the multiple care demands, some CSHCN require prolonged and repeated hospitalizations, becoming dependent on the hospital. In this sense, learning to perform care during hospitalization has been a challenge for the relatives, since the transition to home is related to meeting complex and continuous demands at home.⁷ This transition must be understood as the transition from one state, condition or place to another, where the family member becomes the main caregiver, developing activities, such as: feeding through gastrostomy or nasoenteral tube, handling the infusion pump and applying subcutaneous medication, offering safe care and life maintenance, in addition to meeting the social demands of the CSHCN.

Therefore, in this transition, the educative process must be coordinated by the nurse, with their active participation in the hospital context, preparing the relatives for the clinical and social care of the CSHCN. Thus, it is important to think about educative strategies for the empowerment of these relatives,⁷ in addition to a coordinated and integrated care system to improve the quality of life of children with special needs and their families, as in the United States of America.⁸

As for these educative strategies, it is important to mention that they should not happen in a timely manner, but as part of a dialogical process, thus allowing the collective construction of acquired knowledge, group dialogue and the exchange of information and experiences between members of the group, aiming at the construction of new knowledge among the relatives of the CSHCN and health professionals, especially the nurse.⁹⁻¹¹

The proper transition, using educative strategies implemented in a procedural way throughout the hospitalization period, reduces relatives' anxiety and increases confidence for the care. In this way, it provides continuity of care at home, increases the rate of outpatient follow-up and even reduces unnecessary hospitalizations. The discharge of the CSHCN must always be permeated by liberating educative practices, with Freire's awareness and dialog as the main threads.⁶

Therefore, Paulo Freire's theory of awareness was adopted as a reference, which states that education, to be valid, must start from the concrete man and their concrete reality, considering him as a subject, as this is an ontological vocation.¹² In the educative process with relatives of the CSHCN in the transition from hospital to home, it is where the active participation of students occurs, through

dialogical group practices between educator-student, with exchange of experiences, sensitive listening, ability to accept the other and solidarity. Thus, it is possible to stimulate reflection on concrete reality and leave the position of subject to be an active subject of care.¹²⁻¹³

Therefore, during the transition, when the context of care and professional health caregivers are replaced by the relatives, it is necessary to give a voice to the family, allowing them to express their doubts, fears and awes related to this care. Despite studies pointing out the importance of preparing families for home care, there is no indication of a dialogical educative process with the families of these children.¹⁴

Given the above, the guiding question of this study was outlined as follows: How can the dialogical educative process contribute to the preparation of the CSHCN' relatives in the transition from hospital to home? In order to answer this question, the following objective was defined: To analyze the dialogical educative process as a strategy to prepare relatives of children with special health needs in the transition from hospital to home.

METHOD

It is a qualitative study developed from the Sensitive Creative Method (SCM), which is based on the premises of the culture circle and participatory art-based research, where the researcher uses comprehensive, playful and empathetic devices, making the activity a pleasant and pleasurable moment.¹⁵

As an advantage of this method, the possibility of being used in educative groups to collect/generate research data stands out. This methodological approach is based on implementing the Dynamics for Creativity and Sensitivity (DCS), composed of the triad collective interview, group discussion and participant observation, allowing the production of data in a group way, in addition to interventions by the participants and the cultural animator in a dynamic, dialogic and interactional.¹⁵

The research was carried out between February and June 2018, at the Internal Patients Unit (IPU) of a public hospital specialized in pediatrics located in the city of Rio de Janeiro, where hospitalizations of children from 29 days to 18 years old occur.

Family caregivers of nine children with special health needs in transition from hospital to home were included in the study, totaling nine participants. Inclusion criteria were: Family caregivers from CSHCN with recurrent hospitalizations, more than 02 hospitalizations per year and/or prolonged (over 30 days) at the hospital's IPU, over 18 years of age and who were available to interact in a group. The exclusion criteria were: Hospitalized CSHCN relatives who had cognitive difficulties and did not care for the child, even if they were punctually accompanying.

After consulting the medical records, the participants were selected, who were personally invited by the researcher when they were alone at the IPU, avoiding the embarrassment or the identification that they would participate in a research. In this first moment, the objectives of the study were explained in clear and accessible language and, upon acceptance, a formal invitation was made adapting the date of the dynamic according to the availability of the participants, as well as the entire Free and Informed Consent Term was read (FICT).

To guarantee anonymity, the research members were identified with the code name Participant, followed by an Arabic number corresponding to the order of participation in the dynamic, for example, Participant 1, Participant 2 and Participant 3.

The planning of the DCS Almanac took place after the acceptance of 06 relatives, with a search being carried out in the scientific literature according to the set of care demands presented by the selected CSHCN. Selecting figures, drawings, sentences and words considered not only the demands of care, but also other aspects such as family, education, leisure, religion and social issues.

The listed elements were used throughout the educative process, grouped into the following themes: Clinical care, CSHCN rights, support network, school inclusion, leisure and usual care.

On February 28, 2018, an educative group was implemented implementing the DCS Almanac 1, of the Sensitive Creative Method. In this stage, the objective was to know the learning demands of the relatives of the CSHCN in transition from hospital to home, with the following Question Generating Debate (QGD): To take care of my son at home I need to know...

After the DCS of Almanac 1, the researcher transcribed the speeches of the CSHCN' relatives and identified emerging learning demands, which were worked on during the dialogical educative process.

Subsequently, the educative process continued to seek knowledge, based on scientific literature, according to the demands that emerged: technological (gastrostomy care); modified habitual elements (food preparation and administration by the gastrostomy); clinically complex (set of all demands) and social demands of the care (economic cost of food).

The DCS was held with three other educative groups, on the following dates: Almanac 2 (10/04/18), Almanac 3 (04/18/18) and Almanac 4 (06/06/18), with the objective of working on the learning demands that arose during DCS Almanac 1 and during the educative process.

As for making up groups in the dynamics, it is noteworthy that two relatives, the research assistant and the main researcher composed the first group. In the other groups, in addition to the assistant and the researcher, three relatives also participated. It should be noted that two relatives were found in two different groups.

The operationalization of all the dynamics developed in this study included: (i) presentation of the participants, researcher and research assistant; (ii) explanation of the dynamics and the QGD; (iii) selection and collage of figures, images, phrases and words from different origins for creating collective Almanacs; (iv) collective presentation of the Almanac's artistic production, with the sharing of knowledge amongst the participants and the main researcher, stimulating the dialogue to reach recoding; and (v) group synthesis and validation.¹⁶

Four educative groups were carried out with an average duration of 55 minutes, in previously reserved rooms, in the Teaching Department of the institution where the study was conducted, ensuring privacy and silence. Regarding the researchers who conducted the DCS Almanac, it should be noted that everyone had already held training and capacity building workshops on the Sensitive Creative Method and had experience with conducting and conducting the dynamics. All dynamics had their audios recorded on an MP3 player, with the knowledge and authorization of relatives for an accurate record.

The empirical material was evaluated through the analysis of the French discourse, in its three stages, the first being: constitution of the textual corpus in raw empirical material, which was then transformed into discursive objects; the second, when the discursive object provided guidance on the analytical devices that make up the participants' discourse; and the last, the passage from the discursive object to the discursive process. In this method of analysis, the use of analytical devices to reach the understanding of the meanings produced by the research participants stands out.¹⁷

New groups were created until the construction of the meaning of each demand was understood, since the discursive formation has an influence of psychoanalysis, historical materialism and the philosophy of language, so that each person's history can change, and it is likely that the them will not run out.¹⁷

This study followed the determinations of Resolution 466/12 of the National Health Council. The FICT was signed by all participants, including: The title of the project, identification of those responsible for the research, institution responsible for the research, objectives, criteria for selecting participants, necessary procedures and risks and benefits of the research. The archiving of the

material generated in the study will take place for five years, after completion of the research, and will be under the responsibility of the researcher.

RESULTS

Of the nine participants, six were biological mothers, an adoptive mother, a grandmother and a father, aged between 29 and 59 years old and with an education level ranging from incomplete elementary school to complete higher education. The monthly income of these families varied between the classes No Income (1) and Less than three minimum wages (2), as shown in Chart 1.

Chart 1 – Characterizing the CSHCN and relatives taking part in the research. Rio de Janeiro, RJ, Brazil, 2018

CSHCN	Age	Care demands	Family caregiver	Income
1	3 years	Mixed: medication, modified habitual element and developmental.	mother, 24 years old. Complete high school education	Less than two minimum wages.
2	4 months	Complex	mother, 31 years old. Complete high school education	Less than three minimum wages.
3	9 years	Complex	mother, 30 years old. Complete high school education	Less than three minimum wages.
4	9 years	Complex	mother 32 years old. Complete high school education	Less than two minimum wages.
5	4 years	Complex	mother, 42 years old. Complete higher education.	Less than two minimum wages. Father's salary.
6	1 year	Complex	adoptive mother, 57 years old. Incomplete elementary school education	Without income, her daughter (adopted sister of the CSHCN 6) helps financially when possible.
7	1 year	Complex	mother, 40 years old. Complete high school education	Less than two minimum wages.
8	9 years	Mixed: medication, modified habitual element and technological.	grandmother, 59 years old. Incomplete elementary school education	1 minimum wage.
9	5 years	Complex	father, 37 years old. Complete elementary school.	3 minimum wages.

From the analysis, the following category emerged: The care demands of the CSHCN and the educative process of their families in the transition from hospital to home, submitted below.

The relatives shared knowledge about technological, medicative, modified habitual elements, mixed habits, clinically complex care, social care demands and the importance of the educative process in the transition from hospital to home. The dialogue was produced, but without exhausting the I-you relationship, maintaining the dialogicity in the group and encouraging the exchange between different readings about the demands worked on.

Regarding the demand for technological gastrostomy care, participants 4, 5 and 6 revealed the materials they use to care for the ostium, in cases of gastric waste leakage, and to avoid friction between the low profile catheter and the skin. In addition, they shared care experiences with each other: *we [mothers] use highly absorbent pad when skin [around the gastrostomy ostium] it is not very cool, when it is leaking. And there is the skin protective powder to help treating [the skin contacting the gastric waste], it is a powder for maintaining [the skin] always dry. I don't use on S. [CSHCN 4], because he/she is not there [with exit of gastric waste on the skin] (Participant 4). The non-aborrent gauze to avoid this attrition of the low-profile catheter with the skin. If it becomes humid [gastric waste] I change, I do hygiene. I like to use daily even without leaking [gastric waste on the skin] because, sometimes, [CRAINES 5] there is more sensible skin . There was no the highly absorbent compress and we discovered the non-adherent gauze, it is a chapter option and you can cut nicely, setting it up (Participant 5). It's interesting what the girls [participants 4 e 5] are speaking [on he care with the gastrostomy], I pay attention to all this. The gastrostomy [gastrostomy of the CSHCN 6] is good, it is dry, it is fine (Participant 6).*

In relation to the modified habitual care demands, participants 4, 5 and 6 shared knowledge about the preparation of food and administration by gastrostomy, learned in the hospital, demonstrating that not everything that is learned is capable to be reproduced: *she [nutritionist] advises us [mothers] not to filter the food, but it doesn't work, if we don't filter, it doesn't progress, the probe clogs [extensor of the low-profile catheter], then we [mothers] are obliged to strain (Participant 4). If you cook well [the vegetables] I think it is not needed to use the blender. Once I did not have the diet food [industrialized enteral nutrition], and I didn't want to use the blender, I just sieved it, but I had to sieve it 4, 5 times to get to the texture on going through the probe (Participant 5). I think this is it, what the girls [participants 4 e 5] are speaking [in the educative group]. The nutritionist talked with me about the care with he food [through the gastrostomy] to pay attention especially to the texture. The nutritionist said that you have to make a thinner soup, to use the blender. The nutritionist also spoke about the sugar of the fruit, that one can make juice, but from what I heard [in the educative group] you can't avoid filtering. I don't know from where she [nutritionist] picked up that [not filtering the food, just using the blender] (Participant 6).*

When performing the DCS of the Almanac, it was possible to observe dialogicity between participants 4 and 6 related to special milk, a demand for modified habitual care: *Her diet [CSHCN 6] is not a milk, isn't it? You help me, I asked the doctor and she explained that "there [in the milk] there are more nutrients than the food you eat". So I was happy, because I thought it was milk, just milk (Participant 6). It is a supplement that they [health professionals] say, it's a rich milk, so much so that they live with this milk, get fat, grow, it's a complete diet(Participant 4). I know that if it becomes very difficult for me [prepare food at home], I am going to stay with the milk forever [laughs] (Participant 6). Milk is more feasible for us who have to do many things [at home], you can be sure (Participant 4).*

With regard to the demands for medicative care, participants 4 and 5 shared their concrete experiences on how to administer inhaled medications and medications through gastrostomy: *we [mothers] use the puff [inhaled aerosol spray] in two ways: when the child is not tracheostomized, do with the mask [spacer with oro-nasal mask] and here in this other way [points out to the spray image with no mask] that we [mothers] make directly in the trachea [tracheostomy]. My daughter [CSHCN 4] uses in the trachea [tracheostomy] and it serves as nebulization to help expand the lung. And here is the clock [points out to the clock image], that before speaking anything on dedication, we [mothers] are following the timing. Every controlled drug needs to be taken at the right time to really work (Participant 4). The medication in tablet we dilute [in water] because they [CSHCN 4 e 5] cannot swallow the tablet [they are given by the gastrostomy]. And here [points out to the image] the extensor of gastrostomy, because all medication for those children who have gastrostomy is done*

with the tube, with the extensor [low-profile catheter], than, the sole way to make the medication is injectable [give the medication diluted in the syringe though the gastrostomy extensor] (Participant 5).

Participant 7 shared their concrete reality as a child caregiver with clinically complex care demands and continuous. Due to the prolonged hospitalization time, the same hospital routine is followed at home so as not to cause any kind of strangeness on the part of the CSHCN 7: *I sit down besides the cradle, I keep tapping the butt for the child [CSHCN 7] to sleep and it works, it is already from here [hospital], I adapted everything to my house, the breakfast, lunch, snack time, everything is exactly the same. I have not changed the routine, because he [CSHCN 7] has been already adapted to the food taste here [hospital]. It's more difficult at home because it changes, it's the same seasoning, I learned how to make with them here [cooker of the hospital], but it is never the same* (Participant 7).

Concerning the social demand for care, in the Participant 6 speech, the economic cost of the CSHCN 6 food with special milk is observed: *the doctor said that when she [CSHCN 6] is out [discharge] she will pass another milk, as this one is very expensive. Her current food costs 200 reais [each special milk can], mas after discharge [from the hospital] "we [doctors] will pass the [milk] cheaper one"* (Participant 6).

The traditional education of content transmission, called banking education, was found in the historicity of Participant 3 to take care of the technological demand of the CSHCN 3: *he [CSHCN 3] almost was a child of PADI [Programa de Assistência Domiciliar do Hospital - Hospital Home Care Program]. Only then, instead of asking you [PADI – points out to the research assistant 1], I chose to learn what I needed to do at home and what a nurse does. I learnt everything here [in the hospital], in the hospitalization world [recurrent hospitalizations for being desiderated] of my son [CSHCN 3] that just went out [hospital discharge] after I learnt to use the pump [infuser]. The nurse just set up the step by step [to install the enteral diet in the infusing pump], I looked at the sheet and did at home* (Participant 3).

The dialogic education, creating possibilities for producing or building up knowledge, was found in the speeches of the participants 3 e 4, that emphasized the importance of including other relatives in the educative group: *I think it is cool that other mothers [from Inner Patient Unit] have opportunity to take part [from the educative group], because there are mothers who don't have the experience that we have. We [participants 3, 4 e 5] are already a good time in it [with a child with special health needs], so it's good for us to share and share a little what we know and the new things we don't know. We feel a little safer* (Participant 4). *It is interesting, I did not know [before the educative group] on the hearth rate [high] and face flushing [in the child with high fever]. I never pay attention and my son [CSHCN 3] is white, I have never noted this. Thank you! I think that all mothers [from the Inner Patient Unit] should have been present [in the educative group]* (Participant 4).

DISCUSSION

The relatives of the CSHCN in transition from hospital to home lack new knowledge and skills to meet the demands of care that are closer to the scientific knowledge of nursing than to the family's daily and habitual routine. A study carried out in Chicago points out, corroborating with this research, that education must be a process initiated in the course of hospitalization, occurring gradually and not at the time of hospital discharge.¹⁸⁻¹⁹

The initial experiences of the CSHCN relatives in the hospital environment reveal that they do not feel prepared to meet CSHCN demands, as they face fears, anxieties and doubts, providing less complex care to these children.⁷

With CSHCN care demands, the family caregiver experiences a process of situational transition, where the replacement of roles from family to primary caregiver takes place. In addition to this, there is also an organizational transition resulting from the change in the hospital-home scenario, being

anticipated by the changes that develop in the social, political and economic context, reaffirming transitional care as the essence of the response to the valorization of the human being.

To identify the educative demands, it is necessary for the nurse to propose strategies that enable the recognition of the family caregiver of the CSHCN and the consequent sharing of knowledge¹⁹, as carried out in this study, where the participants shared strategies for taking care of their children at home. Through the learning process, care for CSHCN ceases to cause fear, thus allowing a transition from hospital to home that recognizes the demands of complex and continuous care and promotes the maintenance of life.²⁰

When the transition from hospital to home is not adequate, the CSHCN family member is unprepared due to the distance between the team and the family, a team that focuses only on biomedical care.²¹ Nurses transmit the techniques used in the hospital to the family caregiver only for reproduction, without knowing their reality, suitability and application in the home setting, corroborating the results of this study.⁵

A study conducted in the USA demonstrated that, at home, the family caregiver usually takes care of the CSHCN and other relatives. This accumulation of tasks can result in physical, psychological and emotional overload,²² like what happens with the participants of this study. The family caregiver's concerns are beyond what is remedied by the health team, therefore it is necessary to listen to them, in order to make an adequate preparation in the transition from hospital to home.¹⁴

The inadequate transitions can lead to greater demand for emergency care, failures in medication administration, disorganization of post-discharge care, discontent of the family caregiver and unforeseen costs.²³ In addition, recurrent CSHCN hospitalizations may come to cause problems, such as, financial difficulties for the family caregiver.²⁴

The CSHCN with continuous care demands, clinically complex, have great social demands, requiring an agile health system with programs that meet their needs,²⁵ corroborating the results of this study. Despite the aforementioned, there is no specific legislation that contemplates them, which contributes to becoming residents of the hospital, in order to have their rights met.²⁶

Due to the absence of specific support, financial difficulties are a constant in the life of the family caregiver, in which the expenses with treatment can cost two to three times more when compared to children without special health needs.²⁷ In the United States, the CSHCN with continuous and clinically complex care demands are on the rise and currently account for about 1/3 of total health care costs and 80% of hospitalization costs.¹⁸ The financial difficulty stems from the specificity of care, which, in general, involves high costs, expenses with medicines, special diets and other consumables, which corroborates with the results of this research.²⁷

For this reason, health professionals must guide the relatives about the rights of the CSHCN ensured by Law 8080, of September 19, 1990, *which provides for the conditions for the promotion, protection and recovery of health, the organization and functioning corresponding services*, having as principles the integrality, universality and equality in the access to health, besides guaranteeing supplies and equipment for health.²⁸

It should be emphasized that the effectiveness of an adequate transition depends on the caregiver's approach to their reality in a critical way, highlighting the place of education as an act of knowing reality, unveiling it to know it, remaking the world.¹³ The dialogical educative process favors the transition from hospital to home, as, in the group meetings, the family caregiver problematizes their reality, stimulating reflection and the change from a naive awareness to a more critical one.

The education strategy should be based on liberating practice, respecting the family caregiver, with active participation in the entire process, developing knowledge about the CSHCN' knowable body, facilitating care at home,²⁹ making it possible to reduce the demand for emergency services

and hospitalizations and improving the quality of life for CSHCN.¹⁹ In the case of this study, in addition to the clinical demands, the participants shared knowledge about the social rights of these children.

Direct observation of the care provided to CSHCN by the health team and other families during hospitalization allows the family caregiver to feel more confident,¹⁴ depending on the results of this study, facilitating learning during the educative process and enabling the development of *expertise* so that the relatives may meet the necessary demands.²⁴

The dialogical educative process developed in the group meetings facilitated the sharing of knowledge of the participants, resulting from different spatial and temporal contexts, from the common to the scientific sense. In this exchange of knowledge, the relatives exposed the reality experienced in the hospital and the care for the CSHCN, even if a particular demand were not of their child. Some knowledge that emerged in the group was learned from living in the hospital setting with health professionals and other family caregivers of the CSHCN, contributing to the understanding that knowledge is transformed from concrete reality, through dialogicity, stimulating reflection of the subjects.³⁰

When the family caregiver understands their reality, they can raise hypotheses about the challenge for taking care of the CSHCN at home and looking for solutions. Thus, you can transform your reality and, with your care, create your own world, your self and your circumstances.⁸

The importance of family caregivers of hospitalized CSHCN participating in the dialogical educative process was a contribution of this study, as well as from a research carried out in New York, demonstrating that they develop autonomy, feel safer and empowered to perform care in others contexts, improving efficiency and safety in the hospital-home transition.²³

In Ireland, on the other hand, a study pointed out that health professionals lead the planning related to the preparation of the family caregiver, presenting evidence that parents are eager to participate actively in the educative process together with health professionals to develop and implement health care plans, according to your children's demands.³¹

Research carried out in Brazil showed that CSHCN had more than one demand for care, which increased the challenges for knowledge in the transition from hospital to home, increasing the need for nurses to act actively in favor of learning to care.⁷ Regarding this role of the nurse, the study prepared by the *New Mexico Health Care Transition Task Force* states that these professionals can transform care with their active participation in advisory committees, commissions and councils, using their knowledge to improve political discussions.³²

In the educative process, it is up to the nurse to evaluate the feasibility of carrying out care in the home context, seeking to understand the meaning of these demands for the family caregiver. The team can provide the exchange of knowledge between team-family-parents through programs, meetings and the formation of groups with relatives of the CSHCN, stimulating critical and reflective thinking to transform or reconstruct knowledge.³⁰

For this, the nurse should actively take part in the educative process in the transition from hospital to home, preparing families for the care of the CSHCN and coordinating the dialogical educative process with a minimum programmatic content to be worked on.⁶ It is essential that the nursing professional develops the role of educator and managerial skills, assuming the role of discharge coordinator in preparing the mother and family for home care.²⁹⁻³⁰

In this study, the need for an educative process was justified by the complexity of the CSHCN' demands, which are: Clinically complex, modified habitual element, technological, medicative, developmental, mixed and social demand for care. Therefore, the educative process was developed based on experience, knowledge and *expertise* of the family caregivers, where the health professional was a cultural animator in the group. Finally, it is concluded that the participants of this research educated themselves, and among themselves, mediated by the world.³³

The scenario for data production was a limitation in this study, as it is a reference hospital caring for children with special health needs, especially with clinically complex demands in Rio de Janeiro, which can make it difficult to generalize the results to all other CSHCN.

CONCLUSION

During the educative process, family caregivers exchanged knowledge related to various demands, including: Technological (care with the gastrostomy); medicative (administration of inhaled drugs and gastrostomy); modified habitual elements (special milk, preparation of food and administration by gastrostomy); and social care (food economical cost).

It was found that seven of the nine CSHCN in this study had continuous, clinically complex demands for care, which reinforces the need for the learning of family caregivers to happen gradually during the hospitalization of these children, since they need knowledge beyond the usual and everyday life of the family.

In addition, the dialogical educative process made it possible to share knowledge and exchange experiences, being accepted by family caregivers, highlighting the possibility of teaching and learning to feel more secure in care at home.

In this sense, this study shows that such a process presents itself as adequate in preparing the relatives of the CSHCN in the transition from hospital to home, allowing for the nurses to act as coordinators, suggesting a minimum program content to carry out the dialogical educative process.

This research intends to contribute to the educative process carried out by the nurse, proposing dialogicity, so that, during the transition from hospital to home, family caregivers are heard and that, through reflection, share their knowledge and doubts, making them the safest to perform care at home.

REFERENCES

1. Mattson G, Kuo D.Z. Psychosocial factors in children and youth with special health care needs and their families. *Pediatrics* [Internet]. 2019 [cited 2019 Feb 21];143 (1):e20183171. Available from: <https://dx.doi.org/10.1542/peds.2018-3171>
2. Dias BC, Ichisato SM, Marchetti MA, Neves ET, Higarashi IH, Marcon SS. Challenges of family caregivers of children with special needs of multiple, complex and continuing care at home. *Esc Anna Nery* [Internet]. 2019 [cited 2019 Feb 21];23(1):e20180127. Available from: <https://dx.doi.org/10.1590/2177-9465-ean-2018-0127>.
3. Cabral IE, Moraes JRMM. Family caregivers articulating the social network of a child with special health care needs. *Rev Bras Enferm* [Internet]. 2015 [cited 2016 Oct 06];68(6):1078-85. Available from: <https://dx.doi.org/10.1590/0034-7167.2015680612i>
4. Arrué AM, Neves ET, Magnago TSBS, Cabral IE, Gama SGN, Hökerberg YHM. Translation and adaptation of the Children with Special Health Care Needs Screener to Brazilian Portuguese. *Cad Saúde Pública* [Internet]. 2016 [cited 2019 Jan 26];32(6):e00130215. Available from: <https://dx.doi.org/10.1590/0102-311X00130215>
5. U.S. Department of Health and Human Services. The national survey of Children with Special Health Care Needs chartbook 2009–2010 [Internet]. Rockville: U.S. Department of Health and Human Services; 2013 [cited 2017 Jul 20]. Available from: <https://mchb.hrsa.gov/cshcn0910/index.html>
6. Goes FGB, Cabral IE. Discourses on discharge care for children with special healthcare needs. *Rev Bras Enferm* [Internet]. 2017 [cited 2017 June 07];70(1):163-71. Available from: <https://dx.doi.org/10.1590/0034-7167-2016-0248>

7. Góes FGB, Cabral IE. Hospital discharge in children with special health care needs and its different dimensions. *Rev Enferm UERJ* [Internet]. 2017 [cited 2019 Feb 11];25:e18684. Available from: <http://dx.doi.org/10.12957/reuerj.2017.18684>
8. Novais A, Garneau D. Supporting children and youth with special needs: Rhode Island State Plan 2015-2020. Rhode Island Department of Health [Internet]. 2015 [cited 2019 Feb 11]; Available from: <http://health.ri.gov/publications/stateplans/2015-2020SupportingChildrenAndYouthWithSpecialNeeds.pdf>
9. Viana IS, Silva LF, Cursino EG, Conceição DS, Goes FGB, Moraes JRMM. Educational encounter of nursing and the relatives of children with special health care needs. *Texto Contexto Enferm* [Internet]. 2018 [cited 2019 Feb 13];27(3):e5720016. Available from: <https://dx.doi.org/10.1590/0104-070720180005720016>
10. Gazzinelli MF, Souza V, Fonseca RMGS, Fernandes MM, Carneiro ACLL, Godinho LK. Educational group practices in primary care: interaction between professionals, users and knowledge. *Rev Esc Enferm USP* [Internet]. 2015 [cited 2018 June 30];49(2):284-91. Available from: <https://dx.doi.org/10.1590/S0080-623420150000200014>.
11. Leyenaar JK, O'Brien ER, Leslie LK, Lindenauer PK, Mangione-Smith RM. Families' priorities regarding hospital-to-home transitions for children with medical complexity. *Pediatrics* [Internet]. 2017 [cited 2019 Feb 11];139(1):e20161581. Available from: <https://dx.doi.org/10.1542/peds.2016-1581>
12. Freire P. Educação como prática da liberdade. 40th ed. Rio de Janeiro, RJ(BR): Paz e Terra; 2017.
13. Freire P. Conscientização. São Paulo, SP(BR): Cortez; 2016.
14. Esteves JS, Silva LF, Conceição DS, Paiva ED. Families' concerns about the care of children with technology dependent special health care needs. *Invest Educ Enferm* [Internet]. 2015 [cited 2016 Oct 26];33(3):547-55. Available from: <https://dx.doi.org/10.17533/udea.iee.v33n3a19>
15. Cabral IE; Neves, ET. Pesquisar com o método criativo e sensível na enfermagem: fundamentos teóricos e aplicabilidade. In: Lacerda MR, Costenaro RGS, organizadores. Metodologia da pesquisa para a enfermagem e saúde: da teoria à prática. Porto Alegre, RS(BR): Moriá; 2015.
16. Partelli ANM, Cabral IE. Stories about alcohol drinking in a quilombola community: participatory methodology for creating-validating a comic book by adolescents. *Texto Contexto Enferm* [Internet]. 2017 [cited 2019 June 09];26(4):e2820017. Available from: <https://doi.org/10.1590/0104-07072017002820017>
17. Orlandi, E.P. Análise de discurso: princípios e procedimentos. Campinas, SP(BR): Pontes; 2015.
18. Tian W, Smith PJE, Msall M. Medically complex children and early intervention for comprehensive medical care at home. *Pediatric Annals* [Internet]. 2015 [cited 2019 Jan 25];44(1):36-9. Available from: <https://doi.org/10.3928/00904481-20151226-11>
19. Monnerat CP, Silva LF, Souza DK, Aguiar RCB, Cursino EG, Pacheco STA. Health education strategy with family members of children in continuous medication. *Rev Enferm UFPE* [Internet]. 2016 [cited 2018 Jul 24];10(11):3814-22. Available from: <https://dx.doi.org/10.5205/1981-8963-v10i11a11461p3814-3822-2016>
20. Antonio S, Pacheco STA, Gomes MPF, Bossa PMA, Castro FM, Pereira MCR. Translation of family members' feelings in caring for children dependent on clean intermittent catheterization. *Rev Enferm UERJ* [Internet]. 2016 [cited 2018 Jul 19];24(4):e19990. Available from: <https://doi.org/10.12957/reuerj.2016.19990>
21. Inácio ALR, Peixoto APGL. A assistência de enfermagem e o cuidado familiar às crianças com necessidades especiais de saúde: uma revisão integrativa. *Rev Aten Saúde* [Internet]. 2017 [cited 2019 Jan 21];15(53):87-94. Available from: <https://dx.doi.org/10.13037/ras.vol15n53.4593>

22. Solan LG, Beck AF, Brunswick SA, Sauers HS, Wade-Murphy S, Simmons JM, et al. The family perspective on hospital to home transitions: a qualitative study. *Pediatrics* [Internet]. 2015 [cited 2019 Jan 24];136(6):e1539-49. Available from: <https://dx.doi.org/10.1542/peds.2015-2098>
23. Cruz CT, Zamberlan KC, Silveira A, Buboltz FL, Silva JH, Neves ET. Care to children requiring continuous and complex assistance: nursing perception. *Rev Min Enferm* [Internet]. 2017 [cited 2019 Jan 24];21:e-1005. Available from: <https://dx.doi.org/10.5935/1415-2762.20170015>
24. Okido ACC, Pina JC, Lima RAG. Fatores associados às internações não eletivas em crianças dependentes de tecnologia. *Rev Esc Enferm USP* [Internet]. 2016 [cited 2019 Jan 24];50(1):29-35. Available from: <https://dx.doi.org/10.1590/S0080-623420160000100004>
25. Moreira MCN, Albernaz LV, Sá MRC, Correia RF, Tanabe RF. Guidelines for a line of care for children and adolescents with complex chronic health conditions. *Cad Saúde Pública* [Internet]. 2017 [cited 2018 Jul 30];33(11):e00189516. Available from: <https://dx.doi.org/10.1590/0102-311x00189516>
26. Silveira A, Neves AT. Political dimension to child and adolescent with special health needs care: a reflection. *Rev Enferm UFSM* [Internet]. 2017 [cited 2019 Jan 21];7(2):337-46. Available from: <https://dx.doi.org/10.5902/2179769221976>
27. Okido ACC, Cunha ST, Neves ET, Dupas G, Lima RAG. Technology-dependent children and the demand for pharmaceutical care. *Rev Bras Enferm* [Internet]. 2016 [cited 2018 Jul 30];69(4):718-24. Available from: <https://dx.doi.org/10.1590/0034-7167.2016690415i>
28. Brasil Lei nº 8.080 de 19 de setembro de 1990: Dispõe sobre as condições para a promoção, proteção e recuperação da saúde, a organização e o funcionamento dos serviços correspondentes e dá outras providências. *Diário Oficial da República Federativa do Brasil*. Brasília [Internet], 20 set. 1990, Seção I, p 18055. [cited 2018 Jul 30]. Available from: http://www.planalto.gov.br/ccivil_03/leis/L8080.htm
29. Ramos LDC, Moraes JRMM, Silva LF, Góes, FGB. Maternal care at home for children with special needs. *Invest Educ Enferm* [Internet]. 2015 [cited 2019 Jan 24];33(3):492-99. Available from: <https://dx.doi.org/10.17533/udea.iee.v33n3a13>
30. Coutinho KAA, Pacheco STA, Rodrigues BMRD, Silva LF. Family home care in feeding children with encephalopathy. *Rev Enferm UERJ* [Internet]. 2015 [cited 2018 Jul 31];23(3):318-23. Available from: <https://dx.doi.org/10.12957/reuerj.2015.17762>
31. Brenner M, Larkin PJ, Hilliard C, Cawley D, Howlin F, Connolly M. Parents' perspectives of the transition to home when a child has complex technological health care needs. *International Journal of Integrated Care* [Internet]. 2015 [cited 2016 Oct 25];29(15):e035. Available from: <https://doi.org/10.5334/ijic.1852>
32. Turk, LM, Khalsa SGK. New Mexico health care transition task force: addressing policy and health services needs of children and youth with special health care needs in the state. *The New Mexico Nurse* [Internet]. 2015 [cited 2019 Jan 27];60(2):3. Available from: https://d3ms3kxrsap50t.cloudfront.net/uploads/publication/pdf/1164/New_Mexico_Nurse_4_15.pdf
33. Freire P. *Pedagogia do oprimido*. 29th ed. São Paulo, SP(BR): Paz e Terra; 2000.

NOTES

ORIGIN OF THE ARTICLE

Article extracted from the thesis - Educational process to prepare family members of children with special health needs in hospital-home transitional care, presented to *Programa de Pós-Graduação Enfermagem, Escola de Enfermagem Anna Nery, Universidade Federal do Rio de Janeiro*, in 2019.

CONTRIBUTION OF AUTHORITY

Conception of this study: Precce ML, Moraes JRMM.

Data collection: Precce ML, Moraes JRMM.

Analysis and interpretation of data: Precce ML, Moraes JRMM.

Discussion of the results: Precce ML, Moraes JRMM.

Writing and/or critical review of content: Precce ML, Moraes JRMM.

Review and final approval of the final version: Precce ML, Moraes JRMM.

APPROVAL OF ETHICS COMMITTEE IN RESEARCH

Approved by the Ethics Committee in Research with Human Beings of the *do Instituto Fernandes Figueira – IFF/FIOCRUZ – RJ/MS*, Opinion: 2.482.193, CAAE 78848517.8.3001.5269.

CONFLICT OF INTEREST

There is no conflict of interest.

HISTORICAL

Received: March 30, 2019.

Approved: June 28, 2019.

CORRESPONDING AUTHOR

Meirilane Lima Precce

meiriprecce@hotmail.com

