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RESEARCH

Discourses on discharge care for children with special healthcare needs

Discursos sobre cuidados na alta de crianças com necessidades especiais de saúde
Discursos sobre atención en el alta de infantes con necesidades especiales de salud

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ABSTRACT

Objectives: analyze the discourse of healthcare professionals and families on the continuous and complex care for children with special healthcare needs; understand hospital discharge as a process centered on children demands and family learning. **Method**: qualitative research conducted between 2013 and 2015 through semi-structured interviews, document analysis and the sensitive creative method; the participants were ten children with special healthcare needs, six professionals and eleven family members from a public pediatric teaching hospital in Rio de Janeiro. The data underwent critical discourse analysis. **Results**: at discharge, family caregivers should learn innovative care to guarantee the maintenance of their children's lives at home, but preparation is limited. **Conclusion**: the clinicians and the families pointed out Nurse as the most qualified professional for this preparation, since caring for these children requires nursing care skills.

Descriptors: Child Health; Pediatric Nursing; Patient Discharge; Health Services Needs and Demand; Family.

RESUMO

Objetivos: analisar o discurso de profissionais e familiares sobre os cuidados contínuos e complexos de crianças com necessidades especiais de saúde; compreender a alta hospitalar como processo centrado nas demandas das crianças e na aprendizagem da família. **Método**: pesquisa qualitativa realizada entre 2013 e 2015, por meio de entrevistas semiestruturadas, análise documental e método criativo sensível; participaram dez crianças com necessidades especiais de saúde, seis profissionais, onze familiares de hospital público de ensino pediátrico do Rio de Janeiro, cujos dados foram submetidos a análise crítica de discurso. **Resultados**: na alta, os familiares cuidadores querem aprender o cuidado inovador para assegurar a manutenção da vida de seus filhos no domicílio, mas o preparo é pontual. **Conclusão**: a equipe e a família distinguem o enfermeiro como o profissional qualificado para esse preparo, uma vez que os cuidados procedimentais são cuidados de enfermagem.

Descritores: Saúde da Criança; Enfermagem Pediátrica; Alta do Paciente; Necessidades e Demandas de Serviços de Saúde; Família.

RESUMEN

Objetivos: analizar el discurso de profesionales y familiares sobre la atención continua y compleja de infantes con necesidades especiales de salud; comprender el alta hospitalaria como proceso enfocado en las demandas del infante y el aprendizaje de la familia. **Método**: investigación cualitativa realizada entre 2013 y 2015 mediante entrevistas semiestructuradas, análisis documental y método creativo sensible; participaron diez infantes con necesidades especiales de salud, seis profesionales y once familiares en hospital público de enseñanza pediátrica de Rio de Janeiro, cuyos datos fueron sometidos a análisis crítico del discurso. **Resultados**: en el alta, los familiares cuidadores quieren aprender cuidados innovadores para respaldar la vida de sus hijos en domicilio, pero la preparación es particular. **Conclusión**: el equipo y la familia distinguen al enfermero como el profesional calificado para tal preparación, toda vez que los cuidados del procedimiento consisten en atención de enfermería.

Descriptores: Salud del Niño; Enfermería Pediátrica; Alta del Paciente; Necesidades y Demandas de Servicios de Salud; Familia.

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INTRODUCTION

A study on the profile of children with special healthcare needs (CSHN) and their care demands after hospital discharge found that families need new skills and abilities to perform unique care that comes closer to nursing knowledge than to family knowledge[(1)].

Children with special healthcare needs is an expression used to designate a group of children that present chronic conditions, thus requiring more intensive use of healthcare services and attention from a variety of professionals from a range of specialties, including nursing[(2)].

In Brazil, CSHN are classified in six types, according to care demands. The first, developmental, are those with neuromotor muscle dysfunctions, functional and disabling limitations, under development and functional stimulation. In the technology care category are children using life support devices, such as gastrostomy, tracheostomy, colostomy, etc. In the drug care category, are children under continuous medication, such as cardiotonics, anticonvulsants, etc. In the modified habitual care category, children need adaptive technologies in daily care and in activities of daily living for moving, feeding, dressing, toileting, etc. In the mixed care category, there is a combination of one or more demands, excluding the technology category. In the clinically complex care category, there is a combination of all previous categories, including operation of life support technologies[(2-3)].

Children needing clinically complex continuous care[(3)], during hospital stay, involve family caregivers in the administration of care that satisfy their needs for feeding, oxygenation, elimination, comfort, safety and well-being. Among these types of care, special attention is given to the operation of technology devices, such as nasogastric and nasoenteric probes, gastrostomies and feeding; handling of tracheotomies and aspiration of airways, in oxygenation; handling of intestinal vesicle ostomies, in the elimination of ostiums, among others. They are all fundamental care practices in pediatric nursing for supporting children's lives in the home scenario.

The transition of children with clinically complex care demands from hospitals to homes demands that nurses take on active social roles in the preparation of families for home care, as case manager in the coordination of all aspects of care that involve a variety of healthcare professionals. Thus, institutional care policies focused on these children's discharge started being recommended in studies that addressed the transition from hospital to home care. These policies used to concern the negotiation of responsibility transference from professional care to families, the lack of a support network for family caregivers to manage care at homes, and social factors, impacting this reality[(4-6)].

Experiences with discharge planning of CSHN in other countries resulted in the collective construction of discharge activities by the clinicians and families, in the transition process from hospitals to homes[(7-10)].

With this in mind, it is necessary to investigate the preparation for discharge and its coordination with the demands of families and professionals when handling complex and continuous care for children with special healthcare needs, after hospital discharge. This study has the following objectives: a) analyze the discourse of professionals and family members about continuous and complex care; b) understand hospital discharge as a process centered on children demands and family learning.

METHOD

Ethical aspects

Observing ethical and legal issues related to the research, interviews, document analysis and creativity and sensitivity dynamics (CSD) were conducted only after approval by the research and ethics committee of the institution, study setting, and after all participants had read and signed a free and informed consent form. It should be mentioned that the form was presented and delivered to participants in days other than those when the research was conducted, when a meeting schedule was agreed upon according to participants' availability. Meetings took place in a private place in the institution, reserved exclusively for the research on that day.

Theoretical-methodological frameworks

Learning and performing complex and continuous care for CSHN during hospital stay has been a challenge for family caregivers. As a consequence, qualification of families, through nurses, is a crucial element for these children's discharge. However, it is an educational process that only makes sense if based upon dialog and genuine interest in the true needs and in the autonomy of these families, who should be understood as participating students in the teaching-learning process, according to Freire[(11)], an author who served as theoretical framework in this study.

Moreover, it is worth noting the importance of re-encountering the original meaning of care from Collière's[(12)] understanding, in which caring for is not treating. According to the author, who is also a reference in this study, it is crucial to differentiate between habitual, daily care, which ensures continuity of life, such as feeding, hydration, elimination, warmth, energy, displacement, as well as the need for affection, and restorative care or disease treatment, which aims to limit disorders, fight them and attack their origins. As restorative care prevails over habitual daily care, there is the progressive annihilation of individuals' entire life forces[(12)].

As for the methodology framework, qualitative research was used in tandem with the creative and sensitive method (CSM), which is epistemologically based on critically reflecting on this research, the group dynamics of social psychology and the creation of the artistic type of art-based research. Thus, the method's axes were the creativity and sensitivity dynamics, which group together artistic production, group discussion and participating observation, starting with a debate-generating question (DGQ)[(13)].

Study type

A qualitative study was carried out between 2013 and 2015, associating information obtained from semi-structured individual interviews, document analysis and the creativity and sensitivity dynamics Body Knowledge and Life Line, from the creative and sensitive method(13).

Methodological procedures

Study scenario

The study was conducted in an inpatient unit of a federal pediatric teaching hospital in the city of Rio de Janeiro.

Data sources

For data production, the obtained information was coupled with the semi-structured interview technique with six healthcare workers, document analysis of medical records of ten children with special healthcare needs and the creativity and sensitivity dynamics Body Knowledge and Life Line, with eleven family caregivers who accompanied these children in the pediatric inpatient unit.

Data collection and organization

Six interviews were conducted, one with each member of the clinicians who administered direct care to the children and with, at least, three months of practice at the unit. There was a total of 161 minutes of interviews with a social worker, a nurse, a physical therapist, a physician, a nutrition therapist and a psychologist, which were transcribed verbatim. Workers' speeches were identified by the initials of their professional category (SW, NU, PT, PH, NT, PS).

Eleven family caregivers participated in the CSD. Their CSHN were inpatients, aged between 29 days and 12 years and presented one or more care demands, distributed in four groups, and in eight meetings in total. Family members' speeches were identified according to their coefficient of relationship to the child and name initials (M's mother, R's mother, R's grandmother, T's mother, E's mother, R2's mother, L's mother, LF's grandmother, KV's father, JV's mother, CE's mother).

The CSD Body Knowledge aimed to encourage families to represent, in the body drawing, care procedures that they were learning and/or conducting during hospital stay to care for their CSHN at home. Family caregivers created their artistic pieces mediated by the DGQ: Considering this hospital stay, how and with whom have you been learning to care for your child in order to keep doing it at home?"

This dynamic consisted of presenting to participants a panel with a drawing of a child's silhouette (some participants drew the body) and asking them to use colored pens to write keywords on the drawing, indicating care actions learned and performed by them. This dynamic's length varied from 43 minutes to one hour.

The CSD Life Line aimed to relate the process of caring for their children to their own life history. For this dynamic, the DGQ was: "In your life trajectory, how have you learned to care for your child in the daily routine at home?"

It was conducted with A4 paper sheets hanging from wires with time marks, which related the process of caring for children to phases in the lives of family caregivers (infancy, adolescence and adulthood). In the papers, participants synthesized their key ideas on the question that guided data production and, afterwards, they placed the responses in the parts of the life line that corresponded to when the events happened. The dynamic's length varied from 24 minutes to one hour.

In document analysis, data were obtained from CSHN medical records to complete information on their range of special health needs and care demands. Preparation of families for hospital discharge requires knowledge of children's life conditions, which are frequently understood from speeches of family caregivers, during the CSD Body Knowledge and Life Line. In this stage, a form containing variables related to children and their caregivers was adopted. It had been used previously in a characterization study(1) of an inpatient CSHN population at the institution where the research happened.

Immersion and impregnation in the empirical material pointed to discursive regularity, constancy, consistence and coherence in speeches, reaching theoretical saturation as the criterion for ending fieldwork(14).

Data analysis

For data analysis, speeches were first organized and then linguistically materialized in order to analyze the dialogs to bring them as close as possible to the time of the interviews and dynamics.

In the first analysis movement, the theoretical views and tools of Norman Fairclough's critical discourse analysis (CDA) were employed to understand the relationship between language and social practice. For this analysis, analytical charts were created for each interview and CSD, adopting the three-dimensional model of CDA, in other words, text analysis (descriptive), discourse analysis (interpretative) and social practice analysis (explanatory)(15).

Two thematic units emerged from analysis: innovative care in the change of daily and routine care for life maintenance; and nurse as a teacher of innovative family care.

RESULTS

Innovative care in the change of daily and routine care for life maintenance

The eleven family caregivers participating in the CSD were responsible for the care of 10 CSHN. All children presented more than one complex and innovative care demand and were expected to continue receiving care at home after hospital discharge.

Regarding the origin of the special needs, a close relationship was observed between pregnancy conditions, delivery and birth and the history of special healthcare needs in the lives of most of these children. Congenital (5) and acquired (2) perinatal causes affected eight children, whereas two others presented, in the beginning of kindergarten, special needs as a result of causes acquired at two years of age. These needs generated demands beyond those presented by most children, including technological, medication, developmental and modified routine care or the sum of them; therefore, being clinically complex.

As for technological care, five children had implantable eating devices (gastrostomy); three, ventilation devices (tracheostomy); two had both types of devices and one child depended on non-invasive mechanical ventilation (*biPap*). Regarding medication care, all children were under continuous medication at home; thus, their prescriptions contained, according to the number of children: alkalinizing agents (1), anxiolytics (2), anticonvulsants (6), anti-hypertensive agents (1), bronchodilators (4), corticosteroids (2), diuretics (3), gastroprotectors (2), hormones (1), antipsychotics (1), prokinetics (1), muscle relaxants (1), dietary supplements (1), and vitamin supplements (4).

Modified routine care are adaptations in child care related to feeding through gastrostomy (7 children), daily administration of medication (10 children), prevention of bronchoaspiration (9 children), support for activities of daily living (9 children) (dressing, grooming, cleaning and feeding) and in verification of blood sugar every two hours (1 child). Regarding development care, nine children were monitored continuously by physical and speech therapists.

The discourse of family caregivers portrayed a social practice marked by the need to learn how to conduct innovative care in substitution and/or modification of daily and routine life maintenance care for their children, since the beginning of special healthcare needs in their children's lives, and of the increasing complexity of care demands and their continuous nature.

> *They said my daughter wouldn't be able to eat through her mouth again* [...] *because she would have to receive a gastrostomy, because she wouldn't be able to suckle anymore.* [...] *Why have a gastrostomy, if she has a mouth; she has to eat through her mouth. I didn't understand it.* [...] *But, as time went on, I learned by observing the nurses.* (M's mother. CSD Body Knowledge)

The child with special healthcare needs named M. had her feeding route replaced, transitioning from the oral route to the gastrostomy. Thus, this new situation originates the need to learn how to handle the tools for maintaining children's lives when they return home. Since these new care practices are not transmitted by cultural heritage, it is necessary to learn procedures and how to handle this type of feeding from nurses.

The process of replacing care, mediated especially by nurses, transforms the lives of CSHN and their families, changing social care practices among family caregivers.

> *It was really hard learning how to handle it, because when you had a normal child and now have a special child, it is not easy.* [...] *Stop putting food in the mouth to put it directly in the stomach.* [...] *I learned from the nurses.* (R's mother. CSD Body Knowledge)

> *I learned a lot here with the nurses,* [...] *because when we went home, we didn't have B.* (gastrostomy catheter)*, it was still a probe* (indwelling urinary catheter), [...] *and they taught me how to handle the diet.* (CE's mother. CSD Body Knowledge)

> *Everything was new* (referring to placement and aspiration of tracheostomy). [...] *I thought it was very bad. Terrible. Then after we left intensive care, we went to the ward. I told myself: "I have to decide, I have to learn, I have to feel secure to help my son". Then I began observing and the nurses were very patient with me.* (R2's mother. CSD Body Knowledge)

Speeches reinforce the idea that innovative and complex care is incorporated to the lives of CSHN and their families when a technology for vital function compensation is incorporated to their children's body. When they stop feeding through the mouth and begin using gastrostomies, or breathing with the help of tracheostomies, there is the need for their family caregivers to incorporate new skills and abilities originating from the field and competence of nursing, so that their children can be cared for at home. Because of this, nurses were repeatedly mentioned in the discourses of family caregivers, having introduced nursing care to the social care practices of the families.

> *She* (the daughter) *went to the ward* (after an ICU stay) *and I asked doctor C. how I would do the tracheostomy aspiration. Then she called up a nurse and told her to teach me the aspiration: "Teach her how to do the aspiration"* (manifested intertextuality). (KV's father. CSD Body Knowledge)

In the manifested intertextuality, the caregiving father uses the voice of the physician to define the nurse's participation when teaching him about aspiration of his CSHN tracheostomy. Changes in daily care, such as body hygiene, were also brought up in the speeches of family caregivers.

> *Baths are in the tub.* [...] *The nurse said I shouldn't wet them too much because of the tracheostomy.* (L's mother. CSD Body Knowledge)

> *About baths* [...] *I always learned* (in the hospital) *not to wet them too much.* [...] *You just have to not let her stay in the water too long and neither wet the fixation. Because if it gets wet, you have to change it.* (KV's father. CSD Body Knowledge)

These caregivers learned that, in the baths of children with tracheostomy, one should not wet the children much, should not let children too long in the water and should keep the fixation dry. Many negative discourses transformed the social routine practice of body hygiene for these children into a learning process. also mediated by the nurse.

In short, as CSHN routine and daily care are modified to meet their needs for oxygenation, nutrition, hygiene, comfort and well-being, family caregivers present new learning demands for the field and competence of nursing, in order to guarantee life maintaining care when living at home.

Nurse as a teacher of innovative family care

Family caregivers start their learning demands for unique care during hospital stay, which causes nurses to perform the social role of educators.

> *About the tracheostomy,* [...] *in the first days, the nurses did it and I watched it. But they did it and explained it to me. They not only did it.* [...] *And on the other days, I did it and*

> *they watched me to see if I was doing it right.* [...] *Helping me practice.* [...] *That's how I learned.* (R2's mother. CSD Body Knowledge)
>
> *These things* (gastrostomy precautions) *I learned watching the nurses in action.* (M's mother. CSD Life Line)
>
> *The nurses themselves taught me and I followed them* (talking about gastrostomy and tracheostomy precautions). (R's grandmother. CSD Body Knowledge)

The teaching-learning process of innovative family care conducted by nurses involved explanation, observation, execution, supervision, collaboration and performance assessment. It was a process based on information transmission and demonstration of specific techniques, aiming to enable family caregivers to perform technological care at home. In this same argument line, a caregiving father's speech stood out.

> *I was already close by watching* (the nurses)*, when it was the second, third time, they would ask me to do it. There was always a nurse, when I didn't know. In the first two weeks, there was always a nurse and I was always close by. Then they started saying: "Do you know how to do it, dad?" "I do" "So, you can do it". Then they watched from a distance and it never went wrong* (referring to tracheostomy care). (KV's father. CSD Body Knowledge)

Teaching based on demonstration and feedback appears to be central to this educational process that mediates learning of procedural care. The nurse takes on two roles in this pedagogical relationship of teaching and learning: educator and collaborator, since she helped him in the first two weeks whenever he did not know what to do. After assessing what the father learned, the nurse gave him the responsibility of conducting care, according to what was mentioned in the intertextuality manifested in KV's father's speech.

Thus, decisions on what types of care must be taught to families result from the clinicians demands, particularly nurses. Educational meetings are centered on procedures, on mastering the technique, and on the acquisition of motor skills for safe execution. This nursing practice, equally, was brought up on the speeches of the clinicians and of other family caregivers:

> *Nurses know the maneuvers, know what has to be done,* [...] *there's the whole issue of handling, the issue of doing, the issue of moving, the issue of caring.* [...] *There's great care when passing information,* [...] *when training.* (PS)
>
> *The nurse starts changing bandages, then gives instructions, guidance,* [...] *mainly demonstrating,* [...] *talking but also demonstrating simultaneously.* (PH)
>
> *The nurse kept explaining, kept talking to me, kept teaching me how to do it.* [...] *She did it* (tracheostomy aspiration), *and then said: "Did you understand? Look, I'm coming back soon for you to do it." Then she said: "Now, do it". I took the stuff and did it and she just kept watching.* (L's mother. CSD Body Knowledge)
>
> *They do it to the kid for us to watch and when we think it's safe to try, we do it.* [...] *They have experience with what works and what doesn't work. So, they transfer that to us.* [...] *Now I am doing it.* (T's mother. CSD Body Knowledge)

This reinforces the social role of nurses as educators during the hospital discharge of CSHN, especially when it comes to teaching procedural care, centered on information transmission and technique demonstration.

The nurse's manifested intertextuality reminisces about an encounter with a CSHN mother, reviewing their discharge procedures with a focus on procedural care and seeking the family member's competence and autonomy for technical care:

> *There was a patient that came back,* [...] *so I talked to the mother: "How are you doing? Are you following the instructions I gave you? Is the baby aspiring? She replied: 'Everything is good.' Is the baby secreting?" So, there were no difficulties at home.* (NU)

The interest and concern of the nurse with the performance of air way aspiration by the learning mother are clear, especially when she says everything is well. For him, the family caregiver's response shows her capacity to follow the instructions she learned correctly. Thus, procedural nursing care is transmitted to families so that specific techniques be reproduced, without necessarily criticizing how they were performed and neither why readmission was necessary.

In this pedagogical model, nurses teach procedural care to families in detail (step by step), based on scientific procedures, as can be learned from speeches of family caregivers and of nurses themselves.

> *How to perform tracheostomy suction.* [...] *What to use.* [...] *How to use catheters and compressed air.* [...] *How to turn on the aspirator.* [...] *Ostium hygiene,* [...] *to prevent moisture, to prevent bad smells.* [...] *Skin protection around the tracheostomy.* [...] *Using the oil* (essential fatty acid oil) *because of hyperemia, so it does not swell.* [...] *Fixation replacement.* [...] *Placement of tracheostomy cannula.* (NU)
>
> *Rerouting the gastrostomy catheter.* [...] *The amount of water to fill* (4 ml of water). [...] *The bandage, applying some saline around with a gauze and then applying some D.* (essential fatty acids). [...] *Administering the food while not applying any pressure, leaving it to gravity.* [...] *The soup, cook well, process it in the mixer and then filter it through a sill that is not too fine.* [...] *Place* (the child) *always well elevated, sitting down and elevate the chair* (post-feeding). (JV's mother. CSD Body Knowledge)

In short, the various speeches, which complement each other, show that nurses, in the social practice of educators of families during discharge, shape their teaching according to technical-scientific knowledge of hospital nursing care, which favors care that is basically procedure-centered. Moreover, the educational process is based upon information transmission and technique demonstration, so that the family reproduces at home what they learned at the hospital.

DISCUSSION

Family caregivers of CSHN are faced with innovative care, very different from previous types of care, to guarantee the survival of their children at home. For example, gastrostomy and tracheostomy, which are life support technologies that compensate physical limitations for feeding and breathing, lead to transformations in the life habits of these children and their families according to how much feeding and breathing mechanisms are changed(4-7).

Thus, facing the new realities of families in the social practice of CSHN caregivers, it is necessary to learn how to handle body technologies so that these children can return to their homes. However, these innovative care practices, which were unknown, were not transmitted by cultural heritage, but mediated by nurses in the educational process centered on procedures and technique demonstration.

In this sense, the substitution of daily and routine care practices directly depend on learning new care practices that come from the nursing field, thus requiring action from nurses when counseling/teaching families, since this action is an integral part of nursing care(12,16-17).

Nursing practice is closely related to preparing family caregivers for discharge so they learn how to care for their children at home, focusing on care that will substitute or modify daily and routine care practices previously performed by families and incorporated throughout their lives(10,16-17).

Nurses are the hospital professionals who teach procedures to families of children with special healthcare needs. The professional knowledge of hospital nursing is transmitted to be reproduced at home, according to scientific principles and techniques perfectly justifiable for the hospital environment, with no question as to their pertinence and applicability in the home context. The essence of care is focused on the pathology, in mastering techniques and on the acquisition of motor skills so that all procedures are performed safely(16-17).

Thus, nursing aims to compensate limitations caused by disease and supplement them, if there is not enough capacity to do so. It is based, also, on the comprehension of everything that is crucial to maintain and stimulate a person's life and in search for means and adaptations for such. Moreover, the abilities of family caregivers is encouraged so that they can conduct complex procedures, such as suction of upper air ways and tracheostomy, feeding through gastrostomy, making these family members able to perform this innovative care(8-9).

Demand for innovative, complex and continuous care for CSHN shown in the study includes medication, modified routine care and developmental technologies. However, these family caregivers' CSHN presented more than one care demand, which increased the challenges for learning, in the transition from hospital to home, reinforcing the need for nurse mediation when learning these new care practices.

Thus, the nursing team acts as a facilitator in the negotiation of skills and practices with CSHN families, so that they can be prepared to meet these children's care demands at home(3,8-9).

Feeding and body care practices are the origin of all life habits and beliefs. Thus, it is a mistake to address them and propose changes without seeking to understand their meaning for the individuals involved. Sometimes, new knowledge, originating from the whole scientific process, conflicts with prior beliefs, possibly generating suspicion and insecurity(4-5,12).

However, in the speeches of participants, it was learned that in the pedagogical relationship of CSHN families mediated by nurses, the teaching-learning process of innovative care is more technical-demonstrative than dialogic and centered on learners' demands. Thus, learning how to handle gastrostomies and tracheostomies is based upon explanation, observation, execution, supervision, collaboration and assessment.

It can also be concluded that instructions should always come from professionals to the families, who do not participate actively in the decision-making process related to their children's discharge, since they are mere receivers of instructions given by the professionals. Thus, the pedagogical models adopted are transmission and demonstration, in which abilities and skills are sought in order to execute a specific technique. In this social practice, healthcare professionals (nurses) are the ones who perform the actions, because they initiated an educational process during the discharge moment, not during the hospital stay.

In the banking perspective of education - of deposits, transferences and transmission of values and knowledge - teachers provide knowledge to students as absolute truths, and students receive what has been given to them. However, it is common in this route of action to ignore learners' skills and beliefs, which were built throughout their lives, making it a decontextualized educational process(10-11).

The complexity and specificity of CSHN care also resulted in a learning model centered on reproduction, on content transmission, without critical reflection on adequacy and pertinence for scenarios other than hospitals. Therefore, this educational process has no context, being based upon content transmission and technique reproduction, with no critical reflection on the possibility of maintenance of this care after discharge(16-17). It is expected that family caregivers reproduce at home what they learned at the hospital, with little value given to their knowledge and experience with their CSHN on the social-family context(2,18).

It is crucial to invite families to have active roles when it comes to the clinical practice with healthcare professionals and to conduct educational actions that are based upon their experience, in a true dialogic interaction. In this sense, nurses also need training to develop their educational abilities.

As a result, it is necessary to talk about life sustaining care(12), focused on supporting children's abilities in their daily living demands, such as feeding, bathing, dressing, moving, and playing, even when facing possible adaptations demanded by their health conditions. Thus, it is necessary for nurses to be alert in order to help families reinforce and maintain these abilities that may have been acquired during children's development, avoiding their abandonment and seeking to encourage proper biopsychosocial development, according to the potential of each child.

Finally, it is important to highlight the complex nature of care required by CSHN at home, which make daily, routine and restorative care(12) crucial for their survival, so such care demands need to be problematized, in a dialogic perspective, during children's hospital stay. And in this aspect, nursing has a privileged position, since both perspectives of care are part of its domain, in addition to nurses being recognized as educators, both in the hospital environment and in primary care, when educating family caregivers of children with chronic conditions and technology dependence[19-20].

Study/research limitations

The study was conducted at a high complexity healthcare facility in the city of Rio de Janeiro. The service is a reference in the Brazilian Unified Health System (SUS – Sistema Único de Saúde) for diagnostic investigation and treatment of rare disease, therefore, it can show a reality that does not portray the characteristics of the chronic conditions of most children in the general population. Furthermore, because the research was conducted in an educational institution, clinicians may have more clearly defined roles in the healthcare team, leading them to have better understanding of care demands within the nursing domain. The number of participants represents a limited sample for broad result generalizations. This shows that more studies are needed, with contextualization of practice scenarios and their idiosyncrasies.

Contributions for the nursing and healthcare fields or public policies

The authors expect this research to support professional and institutional strategies and practices that can optimize the transition of children with special healthcare needs and clinically complex care demands from hospital to home, in a way that guarantees continuity of home care with autonomy, safety and quality, and decreases difficulties, doubts, uncertainties, fears and even future readmissions due to avoidable errors. It can also contribute for programmed dehospitalization programs, with the establishment of care policies for home care, avoiding overload of family caregivers and also avoiding making them the only ones responsible for continuous care that is clinically complex, but with a prolonged character.

FINAL CONSIDERATIONS

Discursive and social practices of family caregivers demonstrated that they face the need to learn care that is innovative, transformative of daily and routine care, so that their children's lives are maintained at home while satisfying needs for oxygenation, nutrition, hygiene, well-being and comfort.

These new knowledge demands, which were not culturally inherited, have to be learned through a care substitution process; however, these new skills and practices are based upon the range of fundamental pediatric nursing care, which justifies the frequent mentions of nurses in participants' speeches.

However, in the process of teaching-learning these care practices, nurses, in their social practice as educators, have adopted a traditional pedagogical model, based upon content transmission and technique demonstration, through explanations, observations, executions, supervision, collaboration and assessment. Thus, seeking the acquisition of abilities and motor skills by families for the execution of procedural care.

Furthermore, in this established pedagogical relationship, nurses perform the actions, because they are the origin of the whole educational process; for their part, family members participate as receptors of content. Nurses teach families a range of technical procedures based on hospital nursing skills, ignoring these individuals' life conditions, which makes this educational process decontextualized and reductionist for not meeting the demands of children and families.

The traditional pedagogical model of teaching, based on the delivery of instructions, does not meet the demands of children and families in the sense that knowledge and motor skills alone become the main points of this educational practice, because, being reductionist, it does not guarantee autonomous and safe performance of care at home.

With this, it is crucial that nurses take on the role of discharge coordinators, involving themselves in this transition process and integrating other team members in a group action, offering families support for daily living and building together the means to facilitate the performance of care with autonomy, safety and quality at their homes.

Therefore, beyond the physical dimensions and technical abilities, this process must also consider possibilities, expectations, wishes and hopes of families. Furthermore, it is fundamental to teach these families on where to look for necessary resources and how to be helped in their new path.

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