ORIGINAL ARTICLE

THE ROLE OF NURSES IN CARE PROVIDED TO CHILDREN WITH NEUROGENIC BLADDER FROM CAREGivers’ POINT OF VIEW

O PAPEL DO ENFERMEIRO NO CUIDADO À CRIANÇA COM BEXIGA NEUROGÊNICA NA VISÃO DO CUIDADOR

El papel del Enfermero en el cuidado de niños con vejiga neurogénica desde el punto de vista del cuidador

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ABSTRACT

Objective: to analyze the role of nurses in care provided to children with neurogenic bladder from caregivers' point of view. Method: descriptive, cross-sectional study with qualitative and quantitative approach carried out with 23 caregivers. A questionnaire and the focus group technique were used for gathering information. The descriptive analysis of the data with relative and absolute frequencies was performed using Microsoft Excel 2007 software. The analysis of the interviews was carried out using the theoretical and methodological framework of thematic analysis. The research project was approved by the Research Ethics Committee, CAAE No. 01459612.3.0000.5292. Results: for the caregivers, nurses are professionals who guide the clean intermittent vesical catheterization and organize meetings. It was found that caregivers could not describe other nurses’ activities within the health team. Conclusion: according to caregivers' point of view, nurses participate in managing and caring activities; however, they did not observe the systematization of assistance in which nurses define their role in the team. Descriptors: Neurogenic bladder; Pediatrics; Nursing Professional’s Role.

RESUMO

Objetivo: analisar o papel do enfermeiro sob a visão do cuidador na assistência à criança com bexiga neurogénica. Método: estudo descritivo-transversal, de abordagem quali-quantitativa, realizado com 23 cuidadores. Utilizou-se um questionário e a técnica do grupo focal para a coleta de informações. Com auxílio do software Microsoft Excel 2007, foi feita a análise descritiva dos dados com frequências relativas e absolutas. A análise das entrevistas foi realizada no referencial teórico metodológico da análise temática. O projeto da pesquisa foi aprovado pelo Comitê de Ética em Pesquisa, CAAE n° 01459612.3.0000.5292. Resultados: para o cuidador, o enfermeiro é o profissional que orienta o cateterismo vesical intermitente limpo e organiza as reuniões. Observou-se que os cuidadores não souberam descrever outras atividades do enfermeiro dentro da equipe de saúde. Conclusão: na visão do cuidador, o enfermeiro participa das atividades de gerenciar e do cuidar, não sendo observada a sistematização da assistência na qual se define o seu papel na equipe. Descriptores: Bexiga Urinaria Neurogénica; Pediatria; Papel do Profissional de Enfermagem.

RESUMEN

Objetivo: para el cuidador, el enfermero es el profesional que orienta el cateterismo vesical intermitente limpio y organiza reuniones. Se observó que los cuidadores no podían describir otras actividades del enfermero dentro del equipo de salud. Conclusión: desde el punto de vista de los cuidadores, el enfermero participa en las actividades de administración y cuidado, pero no notaron la sistematización de la asistencia en la cual se define el papel del enfermero dentro del equipo. Descriptores: Vejiga Neurogénica; Pediatría; Papel del Profesional de Enfermería.

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INTRODUCTION

The neurogenic bladder (NB) consists in the loss of normal functioning of the bladder, caused by injuries in a part of the nervous system. Its origin may be related to change of innervations of the bladder wall or the sphincters. This can occur both due to congenital injuries, such as spinal dysraphism, sacral agenesis and myelomeningocele, and to acquired lesions, such as trauma or tumors affecting the nerve roots that emerge from the spinal canal.¹

One of the measures adopted that have proved to be effective in the treatment of NB is intermittent catheterization (IC), which promotes an effective bladder emptying, preventing the occurrence of urinary stasis and consequent formation of post-mictional residue.²

For children with NB, IC is the treatment of first choice to empty the bladder properly and safely, being a valuable tool to achieve continence. Apparently, the wide variety of materials and techniques used for IC does not affect the efficacy and safety of the procedure. However, some basic principles should be followed, such as proper education and training, non-traumatic and clean application and patient's adherence in the long term.³ From this perspective, the specificity of nurses' working process for children with NB should be mainly directed to the binomial caregiver/child, through the elaboration of educational intervention plans, in order to promote the development of self-care skills.

These individual care plans are intended to carry out a clean intermittent catheterization (CIC). This procedure contributes to the cyclic bladder emptying, avoiding distension and the loss of its reservoir characteristics. At the same time, it decreases urinary infection rates and, consequently, generates improved physical, emotional and social well-being of the children and their families, since it enables children's insertion in everyday social activities.⁴

In this respect, the Professor Heriberto Ferreira Bezerra Pediatric Hospital of the Federal University of Rio Grande do Norte (HOSPED/UFRN), which is a reference in pediatric nephrology in the Unified Health System (SUS), created a multidisciplinary program for the follow-up of the families and children with NB at the outpatient care unit. The program started in 2001 assisting children of the nephrology service and in 2004, formalized a partnership with the Association of Children with Myelomeningocele, Hydrocephalia and Cerebral Palsy of Rio Grande do Norte, thus creating the project named ‘Neurinho’, which currently serves 206 registered children and adolescents from 0 to 18 years of age. Given this context, this study aims to:

- Analyze the role of nurses caring for children with neurogenic bladder from caregiver's point of view.

METHOD

This article was drawn from the monograph “The role of nurses in care provided to children with neurogenic bladder from the caregivers' point of view” submitted to the Multiprofessional Residence Program in Children's Care of the Pediatric Hospital, Federal University of Rio Grande do Norte (UFRN), Natal, State of Rio Grande do Norte, Brazil, 2013.

It is a field study designed as descriptive, cross-sectional survey with qualitative and quantitative approach⁵, performed in the outpatient service of the Pediatric Hospital (HOSPED), from June to October 2012. Of 206 eligible participants from the number of children served by the Neurinho project, 23 agreed to participate in the research. The number of potential participants that did not take place in the study was due to the difficulty they had for attending the meetings, because they could not leave their jobs and did not have anyone to leave their children with.

The caregivers included in the study were those who: participated in the meetings during the period of data collection; had received training to perform CIC; and agreed to participate by signing an informed consent form, in accordance to Resolution No. 196/96 of the National Health Council.⁶ Those caregivers who refused to participate in the study were excluded.

The data were collected during the Neurinho Project meetings, every first Thursday of each month, from June to October 2012. This step of the survey took place in two phases: in the first, we used an individual questionnaire, and in the second we performed focal group meetings with a maximum of five participants. Participants were informed about the objectives and methodology of the study and, subsequently, they signed the informed consent form. Anonymity was assured and all the doubts were clarified. In addition, we assured the right to withdraw freely from the participation at any time of the survey, without any cost or prejudice.
At first, as a tool for data collection, we used a semi-structured questionnaire with close-ended questions concerning the identification of the children’s caregivers. In this instrument, we covered the following variables: multidisciplinary follow-up of the children; the primary caregiver who performed CIC; the degree of relatedness between the caregivers and the children; and caregivers’ age, gender, education, marital status, occupation, family income, and type of housing in which they lived.

Focal group meetings occurred through interviews based on a script composed by the following research questions: 1) What are the professionals that participate in the Neurinho Project?; 2) For you, who are the nurses?; 3) Do you consider that the participation of nurses in care provided to your children is important? Why?; 4) What are the activities carried out by the nurses in the Neurinho Project?; and 5) Which are nurses’ contributions to your children?

The environment intended for the accomplishment of the focal group technique provided a calm and reserved atmosphere, without the presence of the children. There were comfortable chairs and air conditioning, which allowed closing doors and windows of the room. We used an audio recorder after the participants’ authorization. The meetings were held without interruption, with everybody’s participation, totaling three meetings.

Initially, in possession of the questionnaires applied, we performed a descriptive analysis of the data using Microsoft Excel 2007 software, in order to make them organized, summarized and intelligible. Subsequently, the data were analyzed for relative and absolute frequencies.

The analysis and interpretation of the interviews were conducted on the basis of the theoretical and methodological framework of Minayo’s thematic analysis. This is constituted of three steps: 1) pre-analysis, i.e., the initial phase that consists in the selection of documents to be assessed; 2) exploration of the material, which deals with the encoding operation; and 3) treatment of the results, carried out through the interpretation and analysis of the information obtained.

After the analysis, three categories emerged: being the mother of a child with NB; the professionals who care for children with NB; and the role of nurses caring for children with NB. Participants’ statements were identified with pseudonyms of fruits to preserve their identity.

The research was started after the approval by the Ethics Research Committee of the UFRN, under certificate CAAE No. 01459612.3.0000.5292 and the authorization by the Research Committee of the institution in which the data were collected. The research was in compliance with the legal precepts of Resolution No. 196/96 of the National Health Council, which deals with research involving humans.

**RESULTS AND DISCUSSION**

- **The subjects of the study**

Of the 23 participants in the study, 91% were female (n=21) and only 9% were male (n=2). The prevalent age bracket was between 20 and 58 years old and most participants were between 30 and 40 years old (60.8%). Of these, 43.5% were married (n=10), 34.8% lived in a stable union with a partner (n=8), 9% were widowers (n=2), 9% were divorced (n=2), and only 3.7% were single (n=1).

With respect to education, 34.8% (n=8) of the participants had finished high school and only 8.7% had graduated from higher education (n=2). Mothers stood out as primary caregiver of children with NB in 87% (n=20) of the participants, 8.7% were fathers (n=2) and 4.3% was the grandmother (n=1). The vast majority of these caregivers was composed of housewives (83% · n=19), followed by self-employed workers (9% · n=2), farmers (4% · n=1), and a computer technician (4% · n=1).

Family income was around one to two minimum wages in 87% (n=20) of the participants and only one caregiver (4%) had income above eight minimum wages. A total of 69.6% (n=16) of the participants lived in their own houses, 17.4% (n=4) of those houses had been granted, and 13% (n=3) lived in rented houses. All of them were masonry houses.

These data corroborate with the literature, according to which the mothers are the primary caregiver of the children, being responsible for their treatment, outpatient follow-up, hospitalizations, therapeutic procedures and complications. These mothers stand out as care providers due to the immaturity of children and as a result of motor and cognitive disabilities that children may present.

- **Being a mother of a child with neurogenic bladder**

The family of a child with chronic illness goes through a period of adjustment. Some problems occur, which are related to psychological and behavioral aspects of the child, who is overprotected. The brothers can
express feelings of rejection and abandonment by the parents. In addition, mishaps in the couple's relationship can occur, because these changes may strengthen or separate them, depending on the existing family dynamics. These reactions determine actions on the part of family members, which imply changes in lifestyle and the mother taking on the role of caregiver of a child with a chronic disease.\textsuperscript{10} The construction of the maternal role is a complex process, which has its origins in the mother's experience as a daughter and gradually processed over pregnancy.\textsuperscript{11}

In that respect, in this study, mothers reveal themselves as primary caregiver, devoting themselves exclusively to their children with NB. In addition, on some occasions, they have to abandon their jobs and/or studies. This fact is confirmed in the statements of some mothers:

\begin{itemize}
  \item \textit{My real need is working, but I'm trying to raise awareness that I can no longer. I've always worked, but after my baby was born everything changed, I just finished college with a lot of struggle, because my mother forced me and she moved to my house. Currently working is difficult, my husband helps me, but he helps when he can, because he works all day long. (Guava) (ipsis litteris)}
  
  \item \textit{Studying is important, but had to stop working, but I'm thinking to go back to school. (Banana) (ipsis litteris)}
\end{itemize}

These statements make it possible to infer that the mothers end up leaving aside their professional growth and care provided to the other children, in order to devote themselves to the children with NB. Most of the time, they are the main and only caregiver. As reported by the interviewees, being a financial provider is the key role of the fathers. This fact was observed in this study, in which only 13\% (n=3) of the mothers received help from third parties for performing CIC.

This way, it is understood that being a mother of a child with NB requires a search for identity affirmation. The birth of a child with abnormalities is a problem that is loaded with guilt socially and culturally assigned to the family, especially to the mother. This fact raises crisis and denial of expectations. It is necessary to adapt the child, which is a process developed in a slowly and conflicted way and that can be experienced as a misfortune.

- The professionals who care for children with neurogenic bladder

It was observed that, for the subjects of the study, the physician is the most recognized health professional by caregivers of children with NB. In this sense, 95.6\% (n=22) of the participants reported the follow-up performed by the nephrologist, followed by the neurologist (47.8\% · n=11), physiotherapist (43.4\% · n=10), plastic surgeon and nurse (26\% · n=6).

The NB interferes significantly in the lives of children and their family members under clinical, therapeutic, emotional and social perspective. In this case, a multi-professional team becomes necessary, in which each professional is responsible for one aspect of caring, acting directly or indirectly together with the families in order to integrate them to social life.\textsuperscript{9}

- The role of nurses in care provided to children with neurogenic bladder

Nurses have their own working objects, means and purposes regarding the development of specific activities, i.e., managing, caring, educating, and researching.\textsuperscript{12} It is necessary to be technically and politically prepared, which implies the identification of the instruments used for the performance of activities related to care management. This will make it possible to opt for holistic caring models involving promotion, protection, recovery and rehabilitation of health, thus directing nurses' work technically.\textsuperscript{13}

The lack of definition of caring methodology is a contributing factor to the loss of the general notion of the nurses' working process. Therefore, the systematization of nursing care is a necessary means to facilitate the working process. Performing unsystematic activities makes this professional a 'tasks performer', generating overload of activities and demonstrating that nothing is done and, at the same time, everything is done, as shown in the following statement:\textsuperscript{13}

\begin{quote}
[... they are [nurses] who take the lead, because the doctors advise, but they are who get their hands dirty. (Guava) (ipsis litteris)]

\textit{We always see that the nurse is beyond the project, even though the doctors are behind them helping, we know that the nurse is always there to help. (Apple) (ipsis litteris)}
\end{quote}

It is observed that, according to the caregivers' point of view, nurses participate in managing and providing care; however, the participants did not observe the systematization of assistance through which nurses can define their role in caring for children with NB. In addition, these
professionals are responsible for building paths that lead to the social inclusion of people with special needs, including education as an activity within the nurses’ working process. With respect to this activity, nurses play an important role in the guidance provided to the family members and the children regarding CIC, what can be proven in previous studies conducted on this issue and confirmed through the testimony of the participants:

When I started [the CVIL] the nurse was who guided me on everything, if I have some difficulty in passing the probe I always look for her, I always come here [HOSPED], even though I live behind a health center. (Pineapple) (ipsis litteris)

[...] Every question that I have, I resort to the HOSPED. Sometimes I’m passing the probe in my son and I can’t remove the urine, so I come back so that the nurse explains everything again and she’s very patient explaining how I have to do it. (Orange) (ipsis litteris)

These statements demonstrate caregivers’ understanding with respect to active nurses’ qualification and participation in providing care to their children regarding guidance on CIC. This point of view is corroborated by several studies that have been conducted on this subject.

These considerations point to the importance of nurses’ role as educators and facilitators of rehabilitation and integration of the individual and his family in society, seeking the adaptation to their health condition, making these children increasingly independent and responsible for their self-care. However, some caregivers expressed the difficulty of health professionals from other services in guiding and performing procedures in children with NB.

CIC training was carried out by the nurse according, by doctor’s advice. When I need to go to the health center and say that I pass the probe in my son, the professionals get scared, thinking it’s a ‘big deal’, and they ask me whether it is not an exclusive activity of the health professional and that it is absurd that I perform this procedure. In order to avoid this type of embarrassment, I come straight to the HOSPED. (Pineapple) (ipsis litteris)

As can be seen, according to the statement analyzed, most health professionals are not yet oriented and informed regarding the reuse of the probe and CIC performed by caregivers of children with NB. A greater deepening about this practice becomes necessary in the training of health professionals at secondary and higher education levels.

It was also observed that even 95.6% (n=22) of the participants recognized the nurses as the main advisers for CIC, only 26% (n=6) of respondents reported that they were accompanied by a nurse:

I think that the participation of the nurse is important, because not always we have the doctors available, there are doctors on consultation days, in the case of illness they are present, but since they’re not always available, the nurse is always available. (Jackfruit) (ipsis litteris)

I’m not very aware of nurses’ role, but the nurse gives all assistance, first we go to the nurse, then the doctor appears, it is like that in all the hospitals I go, it is always the nurse who is ready to assist. (Banana) (ipsis litteris)

The importance of nurses is total; because it is through them that we have contact, the support to pass the probe, caring. They are our anchor point. (Apple) (ipsis litteris)

One of the aspects that drew our attention in that category was the disagreement of information between the questionnaire and the round-table of conversations. In the questionnaire, few cited the nurses providing care to the children with NB, and the participants of the round-table of conversations confirmed the importance of nurses during children’s care. The analysis of the statements allows inferring that the availability and ease of access to nurses by the caregiver end up influencing on knowledge of the nurses’ working process towards society.

It was also observed that beyond the orientation activity with respect to the CIC, the nurses participated in the organization of the Neurinho Project meetings. These meetings contribute to the interaction between caregivers through sharing experiences and also meeting their individual needs, which serves as an anchor point. The following statements confirm this affirmation:

I attend this project because I love it, because it was in the Sarah Kubitschek Hospital where I learned to perform the vesical catheterization. I come for the sake of liking and I increasingly learn something. (Grape) (ipsis litteris)

Since the project began to nurse is forward, she invited me and she always calls to remind me of the meetings. (Grape) (ipsis litteris)

This [HOSPED] is a reference, because through the meetings we learn a lot, even including between us, and we have support between us. (Apple) (ipsis litteris)

These statements reflect the importance and influence that this project has on these families, demonstrating not only the link
between the health professional, the child and the caregiver, but also between caregivers. From this context, it is understood that outpatient activities are fundamental to nursing as an independent practice and caring customization. However, it is important to find pedagogical strategies that make health education more than a way to make people change unhealthy behaviors or just a moment in which the educator can articulate experience of.

FLOW REMARKS

Caregivers of children with NB have limited knowledge about the role of nurses in care provided to their children. Their knowledge is restricted to the guidelines on CIC and the organization of the Neurinho Project meetings.

Nurses must assume the role of supervisors of children that need CIC and their family members, this way contributing to their independence and life quality improvement. This activity represents the qualification of nurses during their academic training. Public network qualification is also important in order to integrate the actions of basic care to medium complexity care and the integration teaching-service, as a strategy of knowledge and dissemination of this technique that has already been used for several years by families of children with NB.

In view of this statement, it is suggested that nurses draw up strategies to make their working process visible, such as: the creation of guidance and follow-up protocols for children with NB and their caregivers; conducting scientific research; and performance of extension projects. In this way, nurses will be able to support and document the activities performed, thereby contributing to the training of new qualified nurses and make children with NB and their caregivers active actors in their living process, thus rescuing their citizenship.

REFERENCES


The role of nurses in care provided to...
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