PERSPECTIVES FROM A HOME BASED NEONATAL CARE PROGRAM IN BRAZIL'S SINGLE HEALTH SYSTEM

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This study aimed to report aspects of how mothers undertake home care of their infants while the latter are kept in a neonatal home care program. It was based on a qualitative approach and institutional analysis related to the gender category was used as theoretical reference frameworks. Data collection was carried out through semistructured interviews with eleven mothers after discharge from the program. Discourse analysis showed that the mothers assessed this form of care as essential, innovative and positive. It is thus considered an effective intervention from a child-integrated-care perspective, since interference of the team in the everyday lives of these women and their children encompassed not only the clinical aspect but affected other dimensions of their lives. It established a partnership with them and helped the mothers to build greater autonomy in caring for their children. However, there is a need for interinstitutional space, which will create the potential for basic health care actions.

DESCRIPTORS: infant care; health programs and projects; home care services; hospital-based; home nursing

PERSPECTIVAS DE UN PROGRAMA DE INTERNACIÓN DOMICILIAR NEONATAL EN EL SISTEMA ÚNICO DE SALUD

Este estudio tiene por objetivo presentar aspecto del cuidado prestado en el domicilio relatado por las madres durante el periodo de internación en el Programa de Internacíon Domiciliar Neonatal. Se adoptó la aproximación cualitativa y se utilizó el análisis institucional articulado a la categoría género como referenciales teóricos. La recolecta de informaciones fue realizada por medio de encuestas semi-estructuradas con 11 madres, después de dar alta del programa. A partir de análisis del discurso, fue posible verificar que las madres evaluaron esa modalidad de atención como esencial, innovadora y positiva. Fue considerada efectiva, en la perspectiva de la integralidad de la atención al niño, una vez que la actuación del equipo en el cotidiano de esas mujeres incorporó no solamente los aspectos clínicos, pero también alcanzó otras dimensiones, estableciendo una relación de colaboración y fortalecimiento de las madres para la construcción de la autonomía en el cuidado de sus hijos. Entretanto, se observa la necesidad de espacios de articulación interinstitucionales que amplíen y potencialicen las acciones de salud en la atención básica.

DESCRIPTORES: cuidado del lactante; programas y proyectos de salud; servicios de atención a domicilio provisto por hospital; atención domiciliaria de salud

PERSPECTIVAS DE UM PROGRAMA DE INTERNAÇÃO DOMICILIAR NEONATAL NO SISTEMA ÚNICO DE SAÚDE

Com este estudo objetivou-se apresentar aspectos do cuidado prestado no domicílio, relatado pelas mães, durante o período de internação no Programa de Internação Domiciliar Neonatal. Adotou-se a abordagem qualitativa e utilizou-se a análise institucional articulada à categoria gênero como referenciais teóricos. A coleta de dados foi realizada por meio de entrevista semi-estruturada com 11 mães, depois da alta do programa. A partir da análise de discurso, foi possível verificar que as mães avaliaram essa modalidade de assistência como essencial, inovadora e positiva. Foi considerada efetiva, na perspectiva da integralidade da assistência à criança, uma vez que a atuação da equipe no cotidiano dessas mulheres e de seus filhos incorporou não somente os aspectos clínicos, mas atingiu outras dimensões, ao estabelecer relação de parceria e fortalecimento das mães para a construção da autonomia no cuidado dos seus filhos. Entretanto, observa-se a necessidade de espaços de articulação interinstitucionais que ampliem e potencializem as ações de saúde na atenção básica.

DESCRITORES: cuidado do lactente; programas e projetos de saúde; serviços hospitalares de assistência domiciliar; assistência domiciliar

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INTRODUCTION

In recent years, there has been an increase in the number of experiences valuing home care as an effective and efficient strategy that offers quality and humanizes health care[1]. However, care in the home environment has been a way of rationalizing the use of hospital beds.

In Brazil, home care for children leaving the Neonatal Intensive Care Unit (NICU) in the Single Health System (SUS) has been incipient. Examples are the experiences of the Fernandes Figueira Institute in Rio de Janeiro, of the *Hospital das Clínicas* at Minas Gerais Federal University and of the Sofia Feldman Hospital in Belo Horizonte[2-3].

Children requiring home care are classified in three groups: children needing palliative care, technology-dependent children and stable preterm infants discharged early to gain weight at home[4]. The first group includes children with a terminal diagnosis, who demand more palliative than curative care. The goal is to promote the quality of life of the child and his/her relatives in coherence with their values and beliefs, regarding them as the center of care. The second group consists of children dependent on technology, such as mechanic ventilation, parenteral nutrition or medication, which will demand medical or nursing care for a long time. The third group comprises infants, including stable preterm babies who do not need intensive daily care, but still demand observation and nursing care, which can be associated with technological support, such as oxygen therapy and feeding through a nasogastric tube[4].

Home care can be considered as a health technology that attempts to guarantee the family's co-responsibility in care without taking away the responsibility of the Health System[1]. In this care modality, it is expected that the parents will be the child's main caregivers and that the health team will act as a support. Hence, the parents' empowerment is the main goal, which is why they are encouraged to develop their care skills[4].

A child's discharge from an NICU is a complex process for caregivers, families and the Health System. While the parents of healthy children feel the increase in social, emotional and physical demands when their children are discharged from hospital, these increase in case of a child with special needs[4]. After discharge, parents of children who received treatment at an NICU present feelings of anxiety, frustration and fear[5].

In this study, we attempted to present aspects of home care reported by the children's mothers during the home care period in the Neonatal Home Care Program of the Sofia Feldman Hospital.

METHODS

To understand the care mothers deliver to their children in a home care service, we decided to carry out a descriptive-exploratory study with a qualitative approach, using institutional analysis articulated with the gender category as a theoretical reference framework. Qualitative research works with the universe of meanings, motives, aspirations, beliefs, values and attitudes, which corresponds to a deeper space of relationships, processes and phenomena which cannot be reduced to the operationalization of variables[6]. Institutional analysis, in turn, reflects the ideas and action modes of the subjects involved in a certain social space[7], in this case the practices of home caregivers. The definition of gender as a category to analyze historical and social phenomena was elaborated by the North American historian Joan Scott in the early 1980's. According to the author, gender is a constitutive element of social relations, based on the anatomical differences perceived between the sexes and, therefore, a first way of signifying power relations[8]. In family care practices, women, historically responsible for work in the private space, have been in charge of developing this care and providing information for care continuity.

Study participants were 11 women whose children were included in the Neonatal Home Care Program (PID-Neo) of the Sofia Feldman Hospital (SFH), between September 2004 and January 2005.

The SFH is a non-governmental, philanthropic organization, located in the Northern Health District in the periphery of Belo Horizonte, which is specialized in health care to women, newborns, children and adolescents. The PID-Neo aims to favor the dehospitalization of newborns at the Kangaroo Care Unit for weight gain, newborns with jaundice who need phototherapy, without risk of exchange transfusion and infants with neurological deficit, tracheostomy or gastrostomy. During the fifteen months of the program's existence, 258 children were attended, 199 (77%) of whom due to preterm birth/weight gain; 23 (9%) for jaundice and phototherapy treatment; 26 (10%) neurological, syndromic, gastrostomized and

tracheostomized; and 10 (4%) for treatment with antibiotics therapy[3].

Data were collected through semistructured interviews with the mothers after discharge from home care. In compliance with ethical precepts, each participant issued a free consent term for his/her participation in the research, in which the theme and objectives were presented, guaranteeing that all information would be treated anonymously. The project was submitted to and approved by the Institutional Review Board at Minas Gerais Federal University. We also used a field diary during the study.

The following questions guided data collection: What did care for the child at home represent? What changed in the living routine while the child received care at home? What facilities/difficulties did you face to deliver home care to the child? Did other persons participate in home care delivery to the child?

The analysis was carried out in line with the following recommendations[9]: ordering of interview data and exhaustive reading of the material; classification of data and grouping by similar themes, capitation of specific categories and final analysis, in which data were submitted to discourse analysis. Thus, the deconstruction and reconstruction of discourse allowed for its organization in four empirical categories - the gain outweighs the pain: the construction of autonomy in care for the child; the home space: fertile ground for the formation of social support networks and solidarity; the women's perception about the Neonatal Home Care Program; The continuity of care for the child after discharge from the PID-Neo.

RESULTS AND DISCUSSION

Description of the socioeconomic profile of the research subjects

Based on the principle that men and women historically construct their social life and their own essence through their productive activity and through the relations established in this praxis[10], we attempted to get to know part of the material and social reality the caregivers are inserted in.

The mothers represented the children's main caregivers during their stay in the PID-Neo. In this research, they were treated as caregivers, mothers and women. In family care practices, women are responsible for developing this care and providing information for care continuity. Nowadays, the mother's choice as caregiver for the sick child at home derives from the historical constitution of family and the woman's role in this context. Therefore, the visibility of this care model intrinsically depends on the questions related to female housework and the woman's social role as caregiver[11].

The mothers' ages ranged from 17 to 43 years, with four adolescent mothers. This reality can reflect the care delivered to this population as, in 2004, 19.4% of births at the place of study involved adolescent mothers[3].

As to occupation, eight were exclusively housewives, three declared that they had a paid job and were general service and production aids. In four of the eleven families, women were responsible for the home. *Per capita* income, calculated by dividing total family income by the number of people in the household, ranged from R$ 42 to R$ 240. It should be added that, very often, the income needed to maintain these homes came from an extensive collaboration network among family members, which is one of the survival strategies used by these women and their families. This finding corroborates a study about women responsible for homes[12], which appointed the increasing responsibility of women in all large Brazilian regions, from 18.6% in 1991 to 25.6% in 2000 in the Southeast. It can also be inferred that these women's greater participation reflects the female activity in the labor market, which increased from 32.9% in 1991 to 44.1% in 2000. However, the authors highlight that the greater female participation should not only be justified by women's voluntary emancipation, but is strongly related with the growing needs for survival, for which men are no longer responsible, because they are unemployed or have abandoned their home[12].

The gain outweighs the pain: the construction of autonomy in care for the child

In this study, it was evidenced that freedom was the main aspect that differentiated home care from hospital care, as observed in the following statement:

The mother understands the daughter. For me, this was the best way. Because here you're free, you're calm, you can act. After I became more secure and knew about the risks of care for her, you get free to help. You become more than a doctor towards your own child to help him when he is discharged. (E8)

The greater proximity between the health team and the caregivers allowed for the designation of care by the professionals, leading to the democratization of information related to the child's health. The result of this interaction can be observed in the following statement:

I thought it was very good, because then I also learned a lot, right? They taught me exactly how to do it. There were a lot of things I didn't know and I found out what it is like. (E7)

The establishment of bonding implies having close and clear relations, permitting the construction of a transference process between the user and the health professional, which serves to construct this user's autonomy[13].

After the initial adaptation period, in which the mothers started to deal with the child and his/her particularities, they felt more secure about care and constructed their own care style. It was observed that, despite the impact of home care for the child on these women's life, they saw the possibility to take care of their child as something more significant. They also apprehended the risks their child was exposed to and the reactions (s)he was subject to during care, which were important elements in the autonomy of this care.

Health professionals' support to women in their decisions is fundamental for them to feel secure to develop the autonomy permitted by the home environment. As a result, they feel capable of making decisions about care which become their own and not only the professionals', enabling them to deliver care to their children.

In this construction of home care, the women's perception and the dialogue with the team were directed at the child's health. These women showed the ability to observe the child well and follow the professionals' guidelines. The insecurity and fear that marked the first days made room for more security, as shown by the following statement:

You have to take care with her posture, observe the tube, see if it was fixed well. Finally, I even learned to fix the tube. Observing if the child has a fever, if she is breathing calmly... (E8)

The construction of care reaffirms the role of mother and caregiver[11]. In the interviews, the mothers demonstrated a knowledge that starts with the child's hospitalization. The PID-Neo is structured as a space to enable these women as caregivers, making possible learning in the environment itself mother and child are inserted in.

The home space: fertile ground for the formation of social support networks and solidarity

During the interviews, we could observe the presence of people who shared housework as well as care for the child with these mothers. In the discourse below, one of the interviewees indicates what this means in care for her son:

My sister is always present. Since the time we spent in hospital. She slept. Then they took the boys away from the ICU, gave a bath, she helped me with everything. She's present since birth and also participated in the C-section, since the moment they took out the boys... (E2)

When they assume home care for the child, the women reported a situation of physical and mental exhaustion, because they conciliate care for the child with housework. They affirmed the following about the greatest help in care for the child:

My mother is my companion. She helped me a lot. If I have to go out today, it can only be with her. She understands my daughter just like me (E8)

The social network is an important factor in adapting maternal behavior towards the child, as the arrival of a child requires new strategies from the family to deal with daily tasks, ability to adapt in order to receive the new member and manage the new demands that emerge in this context[14]. This is a reality for healthy children, but the need for support from solidarity networks is twice as large for children who need hospitalization after birth.

Because it is structured in the family's home environment, the PID-Neo permits greater proximity between the child, the family and the team, promoting the accountability of different actors in care and in the child's development. From this perspective, the care team needs to be attentive in order to seek social networks in the community itself, such as associations and religious groups, which can give greater support to this woman.

The women's perception about the Neonatal Home Care Program

The women perceived home care as an opportunity to grow in care for the child, and the health team appeared as a mediator in this process:

I think that it is a very big opportunity for us to grow inside our home, right? Because, if you stay in hospital, you are a companion, but it is different. It's not like at home. And through the PID, now, we have more opportunity to follow things. It's you at your home, your family, everybody together. (E8)

Considering the definitions of health technology[13], it is observed that, during the home care period, the interviewees had to deal with some kind of hard technology - such as phototherapy equipment, nasoenteral tubes and secretion aspirators. However, soft technology received the strongest emphasis in these women's discourse and is related to the bonds constructed between them and the health team, which allowed for information, education and communication between these actors, with a view to the development of personal skills in care for their children.

Another aspect observed in the statement was the facility the health team's home visits provided to the family:

The doctor arrived here, examined them one by one and weighed them. When one of them had a lot of reflux, the doctor prescribed Motilium. The next day he was feeling great again! (E2)

The mother's stay at home with the child and the team's visits demands commitment and were perceived by the mothers as relations of affectivity, attention and security.

The continuity of care for the child after discharge from the PID-Neo

The feelings the mothers experienced due to the discharge from the PID-Neo indicated that health institutions have a long way to go in order to guarantee the continuity of care and health professionals' support to the children and their families, expressed as follows:

Now that he got discharged I won't deny that I'm a bit scared. I think that, when followed by the doctor, no matter whether he came once, twice or three times per week, we knew that he was coming. And now I'm gonna have to make things happen and always pay attention because, if he needs to, I'll have to rush... (E4)

We identified the need to create a flow in basic care that can guarantee the continuity of care for these children, according to the specificity of their demand. Although the PID-Neo is accredited by the Belo Horizonte Municipal Health Secretary, an articulated flow with the basic care network has not been established yet, which can jeopardize the care delivered to these children.

This makes it possible to obtain a focused integrality that is lost at the moment of discharge, when the team does not establish the bond between this child and the network. However, we should search for expanded integrality[15], which is found in the institutional, intentional and process articulation among multiple focused integralities, centered on each health service, which is articulated in flows, based on the needs of these women and their children.

CONCLUSIONS

This study made it possible to evidence the feelings experienced and the meanings revealed by the mothers during their children's stay in a home care program, appointing the relevance of this theme from the perspective of a neonatal home care program. Staying at home under the supervision of the health team enabled these women as caregivers, allowing them to concretely demonstrate the capacity to learn in the realization of the activities designated by the health professionals.

The woman and the child's presence in the home environment and the team's support grants confidence and the involvement of other relatives in care for the child, permitting the establishment of bonding and the joint accountability of the family and the team for care, enabling them to continue delivering care to the child after discharge from the home care program.

Home care is a humanized care mode delivered to this population. At the same time, from these women's perspective, we observe the lack of effective articulation with other health service entities and identify the need to create a flow in basic health care that guarantees the continuity of care to these children, according to the specificity of their demand.

In this study, we could verify that the mothers assessed this care mode as essential, innovative and positive. It is observed that the PID-Neo made it possible to construct an effective intervention from the perspective of integral child care, as the activities in these women and children's daily reality incorporated not only clinical aspects, but also included other dimensions, by establishing a partnership relation and strengthening the mothers to construct autonomy in care for their children. The PID-Neo can be considered as one of the progressive care stations, which aims to establish the integrality of care for these children, when it articulates a highly specialized care with the basic care service. However, there is a need for inter-institutional spaces that expand and enable the health system.

In this study, we attempted to picture one among a number of incipient experiences, from the perspective of a new care to these children. In line with its objectives, we made no claim on exhausting this theme, as this home care program is under construction, demanding a reflexive practice of this daily reality by professionals and users.

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