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BECOMING A CAREGIVER OF PREMATURE NEWBORNS AND THE DEVICES PART OF THE CONTINUITY OF POST-DISCHARGE CARE

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ABSTRACT

Objective: to analyze the devices part of the continuity of the care for premature newborns and how caregivers experience post-discharge care for extreme premature newborns.

Method: this is a qualitative study, developed from June to October 2013, with data collection using thematic oral history, with ten caregivers, and construction of narratives that have been analyzed based on the references of Deleuze and Guatarri.

Results: the path to become a caregiver of premature newborns is a trajectory of productions of subjectivities, in which encounters, insecurities, faith, avoidance of work and adaptation can be identified. The results indicate that the care for premature newborns must incorporate care practices capable of enhancing the production of life, which implies a non-directed discursiveness of professionals exclusively because of an absence of disease, but which considers the existential projects of the caregivers.

Conclusion: the continuity of the care happens with different care arrangements. However, the role of the caregiver was able to trigger movements and it is a powerful device for the continuity of the care.

DESCRIPTORS: Premature. Discharge of the patient. Continuity of patient care. Nursing. Neonatal nursing.

DEVIR CUIDADORA DE PREMATURO E OS DISPOSITIVOS CONSTITUINTES DA CONTINUIDADE DA ATENÇÃO PÓS-ALTA

RESUMO

Objetivo: analisar os dispositivos constituintes da continuidade da atenção ao prematuro e como as cuidadoras vivenciam a atenção pós-alta ao prematuro extremo.

Método: estudo qualitativo, desenvolvido de junho a outubro de 2013, com coleta de dados utilizando a história oral temática, com dez cuidadoras, e construção de narrativas que foram analisadas, baseadas no referencial de Deleuze e Guatarri.

Resultados: o devir cuidadora de prematuro é uma trajetória de produções de subjetividades, na qual se identificam encontros, inseguranças, fé, evasão do trabalho e adaptação. Os resultados apontam que a atenção ao prematuro deve incorporar práticas cuidadoras capazes de potencializar a produção da vida, o que implica uma discursividade não orientada dos profissionais, exclusivamente por uma ausência de doença, mas que considera os projetos existenciais das cuidadoras.

Conclusão: a continuidade da atenção acontece com diferentes arranjos assistenciais. Contudo, o protagonismo da cuidadora mostrou-se capaz de disparar agenciamentos e é um dispositivo potente para a continuidade da atenção.

DESCRITORES: Prematuro. Alta do paciente. Continuidade da assistência ao paciente. Enfermagem. Enfermagem neonatal.

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INTRODUCTION

Technoscientific advances contributed to the development of the neonatal care, with reduced mortality rates and increased survival of premature newborns with decreasing gestational age.[1] However, it is necessary to recognize that this survival requires inquiries about what has been the life, over the years, of these children and how families experience their post-discharge care.[2]

The continuity of care for premature newborns favors the prevention of problems, hospital readmissions and mortality, and it facilitates the adaptation of the family to the care of this group in relation to the specificities of the care.[1] However, studies have shown that the care focused on the clinical specificities of premature newborns and an interdisciplinary coverage after discharge is not a reality in the context of the health care in Brazil.[3-6]

In the continuity of the care for premature newborns, the care for the family is fundamental, specifically for the caregivers of premature newborns, to guarantee a safe care and adaptation to the prematurity issues. The transition of the premature newborn from the hospital to the household has been revealed to be a process that involves feelings of insecurity in the caregiver, considering that she will take care of a child who has gone through a long period of hospitalization and who has experienced difficulties.[7-8]

With all the complexity immanent to the continuity of the care in the context of prematurity, we have identified in this study that its discussion is timely considering the thematic of networks. The discussion of networks has been proposed by different theoretical and organizational conceptions in the field of Brazilian health care, and in this research we have opted to look at and think about the dynamics of the continuity of the care for premature newborns, seeking a theoretical construction in which the network of care could resemble a rhizome.[9]

The understanding of a network in the perspective of a rhizome presupposes the formation of connective flows that signal an open map, the cartography of the encounters between subjects. This mapping is permeated by multiple connections, which transit through different territories and assume characteristics of heterogeneity, being able to operate in a high degree of creativity.[10] It is appropriate to consider that the constitution of care in the perspective of a network adopted herein is produced in the desire, adherence to the project, political will, and cognitive and material resources, associated with the reorganization of the work process.[10]

We assume in this research that the different (re/der)arrangements, which compose the care for the premature newborn, after hospital discharge, show processes of subjectivation and intentionalities and, thus, territorialization and deterritorialization movements that configure a care scenario. With the above, and considering the relevance of studying how the network is configured in the continuity of the care for premature newborns and recognizing the pertinence in revealing how families have experienced the post-discharge care of these children, this research proposed the following objectives: to analyze the devices part of the continuity of the care for the premature newborn and to analyze how caregivers experience post-discharge care for extreme premature newborns in the municipalities of the state of Minas Gerais, Brazil.

METHOD

This is a qualitative research and the choice of the theoretical framework was made consider-

ing that in the construction of the continuity of the care for premature newborns and their family intentionalities, productions of subjectivities and processes of subjectivation are present. In this study, subjectivation is understood as different ways to produce subjectivity in a given social context, that is, an intensive mode and not a personal subject.[9]

The framework adopted herein allowed us to think contemporaneity and the processes of subjective immanent to it in the perspective of the term rhizome. The idea of a rhizome indirectly refers to multiplicities, not referring to any combination of multiples and ones, but rather, an organization of the multiple as such, which in no way needs unity to form a system. The premise of multiplicities, immanent to the rhizome, brings some theoretical elements such as the concept of movement, which is precisely this growth of dimensions in a multiplicity that changes nature as it increases its connections.[9] Movements or devices can be considered as artifacts that produce innovations that generate events and "becomings". There is an element intrinsic to the movements, that is, the desire understood as a productive and creative force that seeks encounters and which is present in the social context.[11] Thus, we chose this framework because it allows us to identify the multiplicities, the productions of subjectivities, the movements and the devices part of the continuity of the care present in the daily life of the post-discharge care for premature newborns.

Fieldwork was carried out from June to October 2013 in three municipalities of a Microregion, belonging to the Western Macroregion of the state of Minas Gerais, Brazil. To guarantee diversity of contexts, the inclusion criteria of the municipalities were: presenting a higher or lower rate of incidence of prematurity and being a reference municipality for the Microregion.

To include the participants in this investigation, we proceeded with a mapping of the extreme premature newborns, aged between twelve and eighteen months, in the research municipalities, in the Information System of Live Births. In this mapping, we called or made a home visit to invite the caregivers. Ten caregivers, mothers of premature newborns, participated in the research in an oral history interview, a collection strategy that seeks to focus on the world view and version that social players have about their daily life.[12]

The thematic oral histories were transcribed in full and later submitted to a process of textualization, which consisted in the reorganization of the events reported, favoring a clearer text, called testimony, in which we codified the names of caregivers and children born prematurely. The testimonies were presented to caregivers on the second visit, so that they could validate them. After this stage, we read them exhaustively and constructed the narratives. Narratives have diverse theoretical and conceptual conceptions originating from the literature, history, field of communication and psychoanalysis. In this study, we opted for the conception of narratives according to the approach of the field of communication, understood as a process of mediation between individual and society and, therefore, imbued with interlocution.[13] The daily experience, when narrated, gives visibility to the circulation of social sayings, ideologies and realities of everyday life.[14]

The process of analysis of the narratives happened initially with the reading of the material, which enabled a wide visualization of the findings in the field. Subsequently, a process of exhaustive reading of the narratives was initiated, which allowed us to apprehend the central ideas presented by the participants. After this stage, we did a transversal reading, seeking to identify the units of meanings that were grouped into two empirical categories.[15]

Prior to the field work, the research was approved by the Research Ethics Committee of the Federal University of Minas Gerais, according to opinion of number 0339.0.203.000-11. The anonymity of the participants was guaranteed by coding their names (C1, C2, etc.) and they were included in the study after signing the Informed Consent.

RESULTS

The results were grouped into units of meanings that translate the processes of subjectivation and movement in the context of prematurity: becoming a caretaker of a premature newborn after hospital discharge and the care territories and (dis) continuity of the care.

Becoming a caregiver of a premature newborn after discharge

The analysis revealed that home care for premature newborns of the Neonatal Intensive Care Unit (NICU) is permeated by conflicting feelings, because the caregivers affirm that they wish to be at home with their children, but they report feeling insecure, fearing taking care of the premature newborn that experienced an extended hospitalization process and demanded specific care.

In addition to this, there is a reorganization of the daily life of the caregivers to meet the demands of the premature newborn and they recognize that it requires a differentiated care to prevent illness. Even after expressing difficulties and changes, in their daily lives, the participants state a dedication and, most of the times, they state they assume the responsibilities alone with the care of their children.

I was unsure of taking care of P6 at home because she was very small, she was born with a little problem in her nose, so she sucked very little, I was afraid she would choke, suffocate. I did everything after she left the hospital, I had no one to help me (C6).

It was very complicated at first because I had to be especially careful to wash her, sanitize things, I had to use alcohol in everything, because if she caught an infection, it could cause more problems. A premature child demands a lot of care, a lot of attention, they require double the attention of a normal child, because they are very small and helpless (C3).

The period of hospitalization at the NICU was recognized by the participants as a moment of participation and learning in the care for the premature newborn. The experience of staying close to the child during hospitalization allowed for a more relaxed adaptation to post-discharge care.

The analysis also indicated that faith in God was recognized as a device that favors the coping with situations related to prematurity. Despite all the challenges present in the trajectory of these women, faith allowed them to have a feeling of hope, support and comfort in the experience of situations that involve the daily care of the premature newborn.

I give a lot of value to when I was in the ICU, the nurses helped me a lot, they taught me a lot that I did not know. So today I know my daughter inside out. I say that even though I have a doctor, that I have everything, I have a lot of faith in God, I also say that God was greater [...]. *What I want to tell every mother who has a premature baby is that she has to have faith in God* (C10).

The participants experienced complications with their premature children at home, such as: respiratory changes and/or infections, gastroesophageal reflux, seizures, difficulty feeding and weight loss. Hospital rehospitalizations of premature newborns, associated with complications, were reported by three caregivers. The participants also stated that the premature newborns demand frequent appointments with health professionals after discharge. In addition to this, the decision to stop working to take care of the premature child was the decision of seven caregivers, and the demand for care presented by the premature newborn was one of the arguments expressed by them.

Because she was premature she had to have frequent follow-ups and the life of a premature baby is frequently going to the doctor, it's impressive, it's very difficult! (C3).

As soon as she left the hospital she had a reflux and turned purple. I was too scared (C4).

Another thing that was involved was this issue of whether going back to work or not. I wanted to go back, but at the same time I did not go back because she was so little and I was scared (C6).

I went through a difficult period, it was very difficult, but then came the reward and today I'm very thankful, I only have to enjoy every minute with P2 (C2).

Despite the challenges, the participants expressed an adaptation process and stated that, over time, the care of the premature newborn at home was proving to be more relaxed.

The care territories and (dis)continuity of the care

There is a diversity of referrals and different services offered, by the Brazilian Unified Health System (SUS), to premature newborns. We also identified the active search of premature newborns for their care.

When P3 was discharged from the hospital, they had a meeting with me and my husband and told us to look for this and that. The health professionals of the center called and said: today is her vaccination (C3).

From the hospital I left with all the papers for referral, for the stimulation center, I just had to go there and make an appointment. It's easy! (C4).

The analysis reveals the facilitated access to services demanded by premature newborns, with the exception of some medical specialties in the SUS, such as the child neurologist. The strategy used by the caregivers, faced with this situation, is the mixed use of public and private services.

After the discharge it was very good, it was fast. I took her to the pediatrician and she gave me referral to the stimulation center, ophthalmologist and neurologist. Only the child neurologist does not work for the SUS, but since I had health insurance I made an appointment and followed up and she was already discharged from the neurologist (C1).

The caregivers, included in this study, use the primary health care/SUS for the vaccination of premature newborns. Four participants performed

the follow-up care for their children, exclusively, using SUS services. Three caregivers stated that the follow-up was performed in private services (private or health insurance) and three mixed the private services (health insurance) and the SUS.

In addition to the different arrangements in the attempt to favor the follow-up of premature newborns, we identified that the bonding between caregivers and professionals who monitor their children is a potential for the continuity of care. The dialogic, welcoming, continuous, attentive and resolutive encounter is a characteristic that is implicit to the process of forming a bond experienced by the participants.

He [pediatrician] *is a person who when he talks to us he looks us in the eye, he explains everything in detail! He's better than expected. Everything I asked, because I asked a lot, everything I asked he answered me* (C2).

Some participants expressed that, even in the presence of referrals and access to health services, they did not continue with the follow-up. We identified, in this case, the absence of the formation of a bond between the participant and the professionals who cared for the children or, in the case of another participant, the difficulty of maintaining the follow-up because of her employment.

A professional reference, who gives me safety I can't find! I go there, they say it's okay, they look at the growth, the weight, but safety and reference I still couldn't find (C7).

In her follow-ups I couldn't take her, because I was working and the schedules were at the same time. I'm also not going to her childcare anymore, I had to stop doing it because of the work. And I was doing the follow-up at the stimulation center, but I stopped taking her (C5).

The analysis revealed that there was a pilgrimage of one participant to find professionals who could resolve the demand for care presented by her daughter. This search results from the absence of a trust relationship between the caregiver and the professionals. The analysis of her testimony evidenced a pilgrimage in search of care and a production of illness, that is, an absence of autonomy of this participant in the care of her premature daughter.

I haven't found a reference professional yet. At the same time that I can keep doing it, I feel insecure to take care of her, I want to find safety in someone to reassure me. I haven't find it yet. I'm looking for a doctor. We are looking for help, to know what is really right. Then one says one thing, and the other says another thing. Then we go in search of one, then go in search of another professional. But you're doing everything that they ask from you [crying] *and I think I have to run with it now, because then if I leave it for later it won't do any good. So everything that they tell me, that I have the condition to seek, I go, I do. Everything they ask us we do it* (C6).

Data analysis allowed us to identify the chronic condition resulting from prematurity in the daily life of a premature newborn, and this situation triggers feelings of fear and anxiety in the caregiver. The analysis indicates fragility in the access to services by the caregiver in her municipality of residence, which triggered the search for private care in another municipality.

After his discharge, he followed up with a pediatrician, a neurologist, did a test for his little ear and two test for his little head. His appointments were all in Divinópolis, because there is nothing here. Physiotherapy, he did three times a week, now it's two. He went to the ophthalmologist, speech therapist. Then sometimes I get desperate, I'm afraid he will not do things (C9).

In summary, the results presented in this subcategory allow us to identify the devices that favor the construction of an assistance territory for the continuity of care and production of life and also elements that contribute to a discontinuity of care and production of illness.

DISCUSSION

When the premature newborn is discharged from the NICU, mothers express feelings of joy, but they also report insecurity and anxiety, as they recognize that the demands for the care of their children are now their responsibility. There is a reorganization of the daily life for home care marked by the presence of challenges because of the condition of fragility and the different and complex demands of care that the premature newborn requires.[7]

The preparation of mothers for hospital discharge during the period of hospitalization of the premature newborn is a device that favors safety and tranquility in post-discharge care. In addition, there is scientific evidence that actions during hospitalization aimed at preparing the family in the management of the premature newborn reduces anxiety, increases maternal self-confidence in the home care and facilitates the adaptation of the family to the child.[16-17] We must consider, as evidenced in research, that the nurse is recognized as a professional that can favor the process of building the autonomy of parents in the care of the premature newborn during the period of hospitalization.[18] Educational interventions, of parental empowerment, during the period of hospitalization, improve the

parent-infant interaction and reduce the length of hospital stay of extreme premature newborns.[19-20]

In line with other investigations, we have identified that faith can be considered a device used by caregivers to handle the daily challenges of prematurity. A study shows that faith in God strengthens the family to face situations arising from prematurity.[21]

The analysis allows us to infer that it is possible a process of adaptation of the families to situations arising from prematurity despite all the challenges. In the process of adaptation, humans must be considered as always being in movement, in transformation, in becoming, and it is in each new experience lived and in contact with the unknown that they seek to reconstruct the meaning of their experiences.[22]

In the post-discharge care for premature newborns, there is the simultaneous use of SUS and supplementary health services, and this complementarity is a reality in the Brazilian context, configuring itself as a diversity of arrangements in the day-to-day care of users of health services that seek to fill the gaps in the access.[23]

The analysis revealed that the chronic condition resulting from prematurity exacerbates the complexity of post-discharge care at home and requires health services able to meet the specific demands for care required by this population. We need to consider that premature newborns are vulnerable to chronic conditions, and the family, faced with this, may experience situations of crisis and suffering.[23] In addition to this suffering, the conditions can generate a constant search for specialized health care.

The formation of a bond between professionals and caregivers, in the context of health care, proved to be a device that increases the effectiveness of health actions and favors the participation of caregivers. The dialogic encounter to establish a bond between professionals and users and an authentic interest in listening to the other allows a process of accountability and favors a broader perception of the demands and needs put into question.[22]

There is dynamism in the post-discharge care for premature newborns that configures a network in which we can mention the presence of offered services and the referrals between them, active search of the caregivers and their children, creation of a bond and implication of the subjects involved in the care. Considering these constituent elements of the network as strategies that favor the continuity of the care, we noticed that there is a potentiality for this network to work towards a production of life.

We identified that the articulated construction of care is triggered by the desire, adherence to the project in a micropolitics of health work. The recognition of the implication of the subjects as a potential device for the continuity of the care is evident when we identify the relationship between the bonding and the protagonism of caregivers and the effective continuity of the care for the premature newborn.

Desire, in this research, is recognized as essential and immanently productive. Desire generates and is generated in the process of invention and its essence is not exclusively psychic, as in psychoanalysis, because it participates in all reality.[11] Desire corresponds to a power will, a desiring production.[9]

The analysis allows us to infer that the desired productions favor a production of life and an effective continuity of the care. Production of life means, in this research, a process of constitution of autonomy in the way caregivers lead their lives in the complex context of prematurity. Thus, the desirable productions, implicit to the continuity of the care, were evident in the effective constitution of a bond between caregivers and professionals and, also, in the explicit protagonism and decision making of the collaborators who carry out movements in the post-discharge care for the premature newborn.

On the other hand, we also identified the presence of discontinuity of the care that potentiates the production of illness characterized by the pilgrimage and difficulty of the caregiver to obtain autonomy and safety in the handling of the issues of prematurity.

CONCLUSION

The meaning attributed by the participants to becoming a caregiver of a premature newborn shows a trajectory of productions of subjectivities in which different encounters, health practices, demands for care, fears, insecurity, faith, complications, accountability, avoidance of work, adaptation and overcoming create a context of lived experience. Being a caregiver of a premature newborn is a process in permanent construction, and it is also the product of encounters experienced in a unique way by the caregivers, expressing intentionalities.

Faced with the complex process of transition of the premature newborn from hospital to home,

the family needs to count on professional efforts, capable of minimizing their feelings of fear and insecurity. We can notice that these efforts must be initiated before discharge, favoring the participation of the family in the care of the premature child, and more intensely during the first moments during hospitalization, in order to contribute to the adaptation of the family.

The post-discharge care of the premature newborn and the family should incorporate care practices capable of enhancing the production of life. Moreover, we can find in this construction the possibility of a discursivity of subjects in the field of health that will not be oriented exclusively by an absence of disease or presence of normality, but which will also consider the existential projects of caregivers and their families.

The continuity of the care for premature newborns occurs with different care arrangements and flows, as well as with diverse ways that the caregiver can go through the post-discharge care network, but the protagonism of this care, the desiring production, proved to be a producer of effective devices and movements for the continuity of the care.

The development of this research revealed that as important as the services offered, in the context of a care network, the recognition and encouragement of the caregiver as the protagonist of the continuity of the care for the premature newborn is legitimate, timely and necessary. We identified that the movements and devices triggered by the caregivers in the post-discharge care, such as initiative, intentionalities, implication in the care for the premature newborn and the constitution of a bond can trigger actions of resolution in the care and access to services.

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