



## Integration and accessibility of care for children with brain paralysis\*

*Integralidade e acessibilidade no cuidado à criança portadora de paralisia cerebral*

*Integralidad y accesibilidad en el cuidado del niño portador de parálisis cerebral*

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### ABSTRACT

**Objective:** To determine the Brazilian Universal Health Care System (Sistema Único de Saúde [SUS]) health services integration and accessibility of care for children with brain paralysis. **Methods:** This was an exploratory, descriptive, qualitative study. Six families with children who have brain paralysis caused by asphyxia neonatorum and who were residents in Rio Grande, RS, participated in the study. Data were collected in the participants' home through a semi-structured interview. **Results:** Families had difficulties with the SUS health services' integration and accessibility. There were gaps between the care the SUS proposes to provide and the care the families actually received. **Conclusion:** The lack of access to adequate care extends beyond primary care and not always observes reference and contra reference.

Keywords: Cerebral palsy; Asphyxia neonatorum; Child care; Health services accessibility; Child health services/utilization.

### RESUMO

**Objetivo:** Conhecer como as crianças portadoras de paralisia cerebral, decorrente de asfixia perinatal grave, recebem os princípios da integralidade e da acessibilidade do Sistema Único de Saúde. **Métodos:** A investigação contemplou uma metodologia descritiva, exploratória com abordagem qualitativa. Participaram do estudo seis famílias de crianças portadoras de paralisia cerebral decorrente de asfixia perinatal grave. A coleta dos dados foi realizada através de entrevista semi-estruturada, no domicílio dos sujeitos, na cidade do Rio Grande - RS. **Resultados:** A análise dos dados revelou as dificuldades encontradas pelas famílias em relação aos princípios da integralidade dos serviços e ações de saúde e acessibilidade além de evidenciar as lacunas no que concerne ao ideal da assistência prestada pela atenção básica e a realidade a que são expostos. **Conclusão:** A inacessibilidade da assistência não se restringe ao nível da atenção básica, mas estende-se a todas as esferas de atenção, não contemplando a referência e contra-referência.

**Descritores:** Paralisia cerebral; Asfixia neonatal; Cuidado da criança; Acesso aos serviços de saúde; Serviços de saúde da criança/utilização.

### RESUMEN

**Objetivo:** Conocer como los niños portadores de parálisis cerebral, provenientes de asfixia perinatal grave, reciben los principios de integralidad y de accesibilidad del SUS. **Métodos:** La investigación contempló una metodología descriptiva, exploratoria con abordaje cualitativo. Participaron del estudio seis familias de niños portadores de parálisis cerebral, provenientes de asfixia perinatal grave. La recolección de datos fue realizada a través de entrevistas semi-estructuradas, en el domicilio de los sujetos, en la ciudad de Rio Grande (RS). **Resultados:** El análisis de los datos reveló las dificultades encontradas por las familias en relación a los principios de integralidad de los servicios, de acciones de salud y de accesibilidad, además de colocar en evidencia las diferencias entre lo ideal de la asistencia de la atención básica y la realidad de los servicios. **Conclusión:** La inaccesibilidad de la asistencia no se restringe al nivel de la atención básica, él mismo se extiende a todas las esferas de atención, no contemplando la referencia y contra-referencia.

**Descriptores:** Parálisis cerebral; Asfixia neonatal; Cuidado del niño; Accesibilidad a los servicios de salud; Servicios de salud del niño/utilización.

\* Study carried out in the city of Rio Grande (RS).

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## INTRODUCTION

In the final report of the National Health Conference, in 1986<sup>(1)</sup>, the importance of restructuring the Brazilian National Health System was described, expressing the need for creating a Unified Health Care System (SUS), that should represent the construction of a new framework that would dissociate completely health from social welfare; to that end, SUS was introduced in 1990, when law # 8,080 was passed.

The construction of this system, in which all citizens are entitled to health, was guided by the principles of health actions that are: universal, equal and integral<sup>(2)</sup>. Universal means access to health services in all levels of care; equal means that all citizens are equal to SUS, and that they will be cared for according to their needs; integral means the set of articulated and continuous actions of preventive and healing services, individual or collective required by each case in all levels of care<sup>(2-3)</sup>. Simultaneously, the organization of SUS is guided by five principles: regionalization and hierarchy, resoluteness, decentralization, complementarity and participation of citizens<sup>(2)</sup>.

Accessibility has a coverage that goes beyond the availability of resources at a certain time, on a certain place. It should take into account the singularities of hospitals and health resources that facilitate or hinder their use by users<sup>(2-4)</sup>. Accessibility corresponds to characteristics of the places that take up a meaning when assessed at the light of the impact they have on the population's ability to use them<sup>(2)</sup>.

Integral care is the essential connection between health units<sup>(5)</sup>. This connection is established through care networks that recognize the interdependence of each care sphere, since none of them has all the resources and competences needed to solve the problems of a population in all different cycles of life<sup>(6)</sup>.

In this perspective, we may say that the magnitude of care that should be provided by SUS encompasses, in theory, the complexity of health units and actions required by children with brain paralysis due to severe perinatal asphyxia.

About 18 years after its introduction, SUS should enable both universal access to basic health care and to state-of-the art care<sup>(2)</sup>. However, the daily practice as care nurses, has showed that very often SUS principles have taken up a "utopian" role with a gap between the ideology of the system and its practical side, with emphasis on the care provided to children with brain paralysis, since these individuals together with their families, have to face situations that harm their rights as citizens<sup>(7)</sup>.

Under this perspective, the following questions were raised: Is care given to children with brain paralysis due to severe perinatal asphyxia contemplating the principles of integral and accessible care? How do these children's

families perceive primary care? Do they have access to the family health strategy (ESF)?

To answer these questions, the objective of the present study was to know how children with brain paralysis due to severe perinatal asphyxia receive the principles of integral and accessible care at SUS.

## METHODS

To perform the present study, a descriptive and exploratory methodology was used with a qualitative approach. It is qualitative because it tries to incorporate the meaning and intention of the use of the principles of SUS integrality and accessibility by children with brain paralysis and their families.

The choice of individuals was carried out to encompass all families with children born with APGAR lower than or equal to three in the fifth minute, that is, when there was the diagnosis of severe perinatal asphyxia, in the city of Rio Grande - RS from 2005 to 2007. Individuals were searched through two stages. The first stage was characterized by selecting individuals who were taken from another study written by the authors called "*Estudo da prevalência do nascimento de crianças portadoras de necessidades especiais*" (Study on birth prevalence of children with special needs) approved under number 030/2007. This study allowed for the stratification of all births in the city of Rio Grande in the years 2005, 2006 and 2007, so that all children with APGAR equal to or lower than 3 in the fifth minute of life could be searched. There were 32 newborns and seven survived. The second stage of the study was to search these children. One of them was not found and the total was six children. For data collection, we have chosen to interview first children's caregivers, and we believed it would be the mother. However, in two cases the researchers found the need to include also two maternal grandmothers and one maternal grandfather because they were considered as the children's caregiver. Thus, the study has six families and nine participants that were identified by the pseudonyms F1Mother, F1Grandmother, F2Mother, F2Grandmother, F2Grandfather up to F6Mother, respectively, according to the order of the interview and the kinship with the child.

The research project has been sent to and approved by the Research Ethics Committee of the Associação de Caridade Santa Casa do Rio Grande, under number 002/2008. Individuals were contacted in their homes and invited to take part in the study. When the proposal was explained, participants were requested, according to Resolution # 196/96 of the National Health Council, to give their written consent, signed in duplicate, one remained with the participant and the other with the researchers. The legal and ethical aspects have been

emphasized and they could give up their participation at any time with no personal harm to them or their children. Anonymity and secrecy was assured.

Data have been collected through a semi-structured interview which was recorded after participants' approval. We chose to assess data through a thematic analysis with three stages: pre-analysis, data exploration, treatment and interpretation of the results obtained<sup>(8)</sup>.

## RESULTS

The following two themes emerged from the data analysis: Care integrality and accessibility for children with brain paralysis and Basic Health Care Unit (UBS): is it a place for vaccination?

### Integrality and accessibility of care provided to children with brain paralysis

Statements from social actors of this study showed the absence of an integral care to children with special needs due to brain paralysis. There was no hierarchy in care among the levels of care either a referral or counter-referral between them.

*They referred him, he has appointments every month at FURG, in Pediatrics, neonatal in Pediatrics with the Physician (name) all months he is followed-up [...] he was referred by the pediatrician who discharged him from hospital [...] She only referred him to an ophthalmologist when he was four months because they believed he had something in his eyes, they thought he could not follow movements, then I took him to the eye doctor three times and up to know they have not found anything in his eyes (F1Mother).*

*They did not tell me anything, not that I can recall of (F2Mother).*

*When she was discharged from hospital they told me to do the newborn screening, I did not go to the health center, I took him to do it on the laboratory where my sister works because they do the complete test there (F3Mother).*

Integral health care of children with special needs is also prevented by the difficulty individuals have to access health care units.

*To get an appointment here at the health center is very difficult, [...] there are people who come in sick to get a number, at five in the morning and they stay on the street, it rains, it pours, and they stay there, there is no roof, or a covered area for them to stay, so they stay there until eight o'clock in the morning to get a number [...] And the worst thing is that you get the number and many times you are not seen, you have to get back the other day. How do you get back? (F2Grandmother).*

*[...] my mother does not like to take her to the health center*

*because we go there and wait for hours and hours [...] it takes too long, to be seen, my mother herself has an agreement with the drugstore and she buys the medications, she knows what to do (F2Mother).*

*They sent me to a speech therapist, but I did not go because there was too much bureaucracy to undergo, such as getting the number, for me to be able to get a number for him I had to wait in line and it was chaos. I used to leave home at seven, my mother-in-law took care of him, but I could not leave him for long because he was too young, she did not know how to handle very well, right? So I arrived there and the numbers had already been given, I could not schedule the appointment. Then I tried once again and I told him (husband) I give up, let it be, let him stay here with me (F5Mother).*

*I don't go too often to the health center, because it takes too long to get a number, you have to arrive very early to get one, sometimes you get there and the numbers have been given away (F6Mother).*

Inaccessibility to health centers brings many consequences such as in the case of the child identified as N5 who was referred to speech treatment and she could not have access to the system which made F5Mother give up treatment. Likewise, F2Mother states that because it is difficult to get care, F2Grandmother is the one medicating the family members and the child with special needs with no scientific preparation.

### Primary Health Care Unit: a place for vaccination?

From data analysis, we learned the view that these children's families have on primary care units, which demonstrated absence of idealization of the services to be provided by these units and the reality experienced by these families.

*Here at the center I just take him for vaccine [...] doctors are never here, there is a small sign there, physicians Tuesday, Wednesday and Thursday, so you cannot be sick on another day (F1Mother).*

*We always take him to FURG [...] we took him to the center last year, when the physician was there for an appointment [...] the rest of the times, we just took him for vaccines, right (F1Grandmother).*

*Look at her now (children) she does not go very often, she used to go before for vaccines (F2Mother).*

*I just took her to this center for vaccine, because to schedule an appointment with the physician is only possible at FURG [...] it is very difficult here, and also at FURG they already know her, they have taken care of her since the beginning (F3Mother).*

*I went just for vaccines [...] oh, honestly, I prefer it, I've already*

*told you, we have help with everything, my father pays for the health plan, but I think that if I had no money to pay I would do everything I could to pay, I think it is a bit, how can I say... slow, sometimes you have an appointment and then you stay there on the line, waiting for care that children are not supposed to wait, it is an emergency [...] (F4Mother).*

*I just go for vaccines (F5Mother).*

*I go to the center just for vaccines, but I don't take him there for appointments, I take him to the Pediatrician at FURG, which is where they know everything that happened to him, in this case, his problem, I do everything there, when I get scared I take him there [...] They know what happened to him [...] I take him for vaccines here (center), but medical follow-up at FURG. As I had him there, everything is easier, you just go there and schedule, I take him there for treatment (F6Mother).*

As for care provided by ESF, the answer was total lack of knowledge of the studied population on this strategy.

*As girls that work here on the street you say [...] Look at this lady that works there, when he came home, they came here, the chief nurse (name) and the other lady that works in the center and lives in my street, that girl that works as a community agent, she also came with her (I asked what they were doing in her house) They knew he had been admitted and then they came here to see how he was doing (Did they tell you anything, offered help?) No (Mother 6).*

F6Mother was the only one receiving home visit; all the other families mentioned that no one from the center had visited them.

## DISCUSSION

Statements show that families were not covered by the hierarchy and integrality of health care. Follow-up of children observed by families was guided; however, it had to do with biomedical follow-up centered on the disease.

This has been observed almost every day in Brazilian health institutions which work developing historical practices, socially determined by the actions of the physicians<sup>(9)</sup>. The needs of brain paralysis patients should be met and should be the focus, attempting to find answers to their vulnerability.

A child with severe perinatal asphyxia has to be sent/referred to a service network that goes beyond medical care. To foster their growth and development the complex network of services available at the health sector should be integrated<sup>(7)</sup>. Care needs to extrapolate even the multi-professional barriers and be intersectoral, so that a joint

effort between health, education, recreation, early stimulation, among others can be performed. Units providing care services with different levels of complexity form the whole that cannot be divided; they must shape a system to provide integral care<sup>(2)</sup>.

“Integral care extrapolates the hierarchical organizational structure and regional health care; it is prolonged by the real quality of individual and collective care ensured to health system users”<sup>(10)</sup>. Thus, so that care provided to children and family is considered integral, it should also visualize family as a whole, contextualized in an environment with beliefs, cultures, and singularities. It is not enough to guide and refer families to a more complex care for children with brain paralysis. Services and health actions need to make guidelines effective, with a feedback to assess results obtained. Furthermore, whenever possible, services should establish an interaction to discuss the advances obtained and to plan, together, new care strategies to meet the needs of this group.

Inaccessibility demonstrates that services offered cannot meet the demand. A similar situation was also found in a study previously developed<sup>(2)</sup>, which concludes that the health system demonstrates a disproportion between the supply and demand of services, leading to waiting lines, and physical and emotional wear of users. Access to services and actions offered by the system has been narrowing, due to the lack of continuity in health care, triggering a “domino effect” which leads to a non-fulfillment of the principles of integrality.

The speeches show the difficulties faced by families to have access to the UBS. These primary health care units are not “simple” UBS, but rather primary units of family health teams and according to their principles, demands must be freely met not with ‘numbers’ and a limited number of visits.

The lack of access to services harms not only citizens’ rights to care but also puts health integrity of these citizens at risk because they end up giving up treatment or resorting to self-medication because of the delay of the system.

From the statements made, and aware of the relevance of integral and accessible health care, we wanted to know from social actors of the study the health services they have access to.

The hospital and outpatient unit Fundação Universidade Federal do Rio Grande (FURG), were described as the main services they have access to. However, we should pay closer attention to statements to understand that with all the difficulties described regarding access to UBS, families do not go to it because professionals working there do not know the infants’ history which is extremely relevant to the families. This issue reinforces the need to create or even to enhance the

existing referral and counter-referral systems so that the knowledge on patients' history is not restricted to one institution but rather available to all care levels through automated strategies on an online system. Statements show devaluation of primary care, it is considered as a service for vaccination. The criticism is not to depreciate the relevance of vaccination, but rather the care provided by primary care because it is not only supposed to immunize children but to protect and promote health and to that end, several tasks must be performed contemplating integral health care.

Different from what is said by the hegemonic-physician discourse, primary health care is not a simplified action. When it is taken up integrally and with resolution, professionals involved in it must perform several actions, attributes and use technological resources<sup>(9)</sup>.

On the other hand, the studied population does not know the real role of primary care. This leads to anxiety and raise the following questions: Why are these families not aware of the role of primary care? Is this care model the only one that was introduced to them? Do they see it depreciated because they are impregnated by the rule of the biomedical model which is centered in the disease? Why do these UBS with family health strategies cannot reach their participants even if there is an impending risk? Are there referrals or counter-referrals by health institutions?

The study does not answer these questions since they are not the objectives of it. However, it showed that individuals do not know primary care, and this also occurred when we asked them if their region had an ESF. The answer was a question mark on what was being asked. Families did not know if there was Family Health Strategy in their areas because they did not know what ESF was.

This situation is the opposite of what is expected for an ESF, since primary care at SUS is in addition to users'

"entrance door", responsible for solving about 80% of the health demand. Additionally, it should replace the current hospital-centered model, by the model of health promotion, taking health closer to families<sup>(11)</sup>.

Family Health Units work based on their own principles: integrality, integral care in all levels of complexity; division by territories and enrollment of patients, units work with a defined territory and the population must be enrolled and followed-up by a multi-professional team<sup>(11)</sup>, formed by several health professionals working in an integrated fashion to build health in a collective sense.

## FINAL CONSIDERATIONS

The study enabled to know difficulties experienced by infants and their families regarding integrality and accessibility to health services and actions that should be available at SUS, since health is citizens' rights and a duty of the State.

The recommended by ESF differs from the reality found and demonstrate the inaccessibility of individuals regarding care. This lack of access to care is not restricted to primary care, it also extends to all care spheres, such as referral and counter-referral, which is harmful to this highly vulnerable group. Therefore, care provided to this part of the population should be reviewed so that rights are not denied by inconsistencies in the system.

The Family Health Team, in theory, is trained to know the families they are responsible for. When they know their singularities, they can identify their main health problems, risk situations, and care needs for healthy growth and development. Therefore, this team should follow-up the studied families because they were at risk, requiring a high level of care. Not knowing about the EST shows that there is still a long path to reach the goals of integral and accessible care that is beneficial for children's growth.

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