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Full Length Research Paper

Experiences of two Brazilian families with the birth of premature extremely low-birth-weight infants up to five years of age: Use of narratives

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This study was carried out to know about the experiences of two Brazilian families with the birth of extremely premature infants up to five years of age. Participant observation and open interview were used as qualitative methodology. Tertiary teaching hospital, residences, schools and churches families attended. Fathers and mothers of two extremely premature infants assisted to Neonatal Unit, January/December 2001. There were 21 meetings, 14 for observation (30 hours, 90 field diary's pages); seven for interviews (eight hours, 117 pages transcribed). The analysis is by semiotic model. This report is presented as two narratives. Four great themes were identified by narratives: healthcare, parents' stress, communication and support network. Gestational hypertension was a risk factor for extreme prematurity, prolonged neonatal care and families-neonates' separation; mothers' assistance at delivery room and first entry in Neonatal Unit had disrespected humanized care; parents' stress was present at delivery room, first sight of the newborn at Neonatal Unit, at home, as child's caregivers, with child's morbidity, fear of death has always been present; communication was both positive and negative; nuclear/extended families, friends, health team and religion were the social support network's elements. The narrative brought to debate relevant issues.

Keywords: Premature, family, intensive care unit, neonatal, narrative, qualitative research**.**

INTRODUCTION

Parent-child separation as a consequence of admission of a premature newborn (NB) in a Neonatal Intensive Care Unit (NICU) immediately after delivery generates high level of stress to their parents (Eriksson and Pehrsson, 2005). Knowledge of the effects of a premature extremely low-birth-weight (ELBW) infant's birth on the family focuses on publications written in a language that Camargo Jr. (2003:125) called *hard sciences of the field of biological.* As one more possibility, qualitative methodology, a tool of human science has been used for Health research (Pereira and Cardoso, 2005). Different origins, cultures, religions and socioeconomic levels act upon behaviours and feelings that determine how parents deal with the birth, growth and development of ELBW infants.

Narrative, a powerful instrument to express experiences of pain and suffering is integrated with

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List of Non-Standard Abbreviations

ECU -	Emergency Care Unit
ELBW -	Extremely Low-Birth-Weight
ICU	Intensive Care Unit
IU -	Intermediate Unit
NB	Newborn
NICU -	Neonatal Intensive Care Unit
RJ -	Rio de Janeiro
SEH -	Servidores Estado Hospital

qualitative methodology. The story of a human being that existed at that time and that space gone by, will exist while someone narrates it (Heller, 1993). The narration of a medical case covers themes that the conventional clinical history does not cover, such as perception of falling ill, response to diseases, difficulties and hopes in the doctor-patient relationship, acceptance or rejection of the treatment. With narrative competence, good doctors use technological advances, calm fears and relieve pain without disregarding individual choices (Hunter, 1991). The narrative has a sequence: beginning, events that unfold and an end. It presupposes a narrator and a listener, whose different viewpoints become evident in the way stories are told (Hydén, 1997).

The aim of this study is to narrate the experiences of two Brazilian families, according to their viewpoints, with the birth of premature ELBW babies until they reach five years of age. It was based on the assumption that extreme prematurity transforms family history and influences the identification process that mothers and fathers build for themselves and for their children.

SUBJECTS AND METHODS

The stories of two Brazilian families in which occurred the birth of a premature ELBW infant subjected to neonatal intensive care was known through the use of qualitative methodology and narrative.

Subjects

The subjects are mothers and fathers of two NBs whose inclusion criteria were: birth weight below 1000g; admitted to the NICU of Servidores Estado Hospital (SEH), a public, tertiary, educational hospital, Rio de Janeiro (RJ) city, from January to December 2001; discharged from the NICU; follow-up visits at the SEH outpatient clinic; living in RJ city; whose families agreed to participate in this study. At the beginning of the study, the children were five years old. The time elapsed since the child's birth associates the current reality to the memory of events, not too close not too far.

Data on gestation, delivery, hospitalization and follow-up were obtained from medical records. The qualitative data were collected by participant observation and open interviews used to learn their life stories. Participant observation aimed to build a closer relationship between the researcher and the family.

Participant Observation and Interviews

The study locations where participants observations were conducted included the hospital, where care was provided, and the social areas as families' homes, schools and churches that the children attended. The approach was reflective and interpretative. Everything that was observed, as the description of the scenarios, actors and dialogues was taken down, transforming conversations, observations and experiences into written texts, the so-called *field notes* that, collected formed the *field diary.*

The interviews with the four informants, fathers and mothers were conducted at the participants' homes. Questions were open-ended and narrative-oriented, which meant that the parents were encouraged to talk about their experiences in ways that would elicit free telling stories. One single open question was put at the beginning of the interviews: *Could you tell me about your experience with the birth of your premature ELBW baby until now?* Most parents responded by telling a story that included what happened, different people that were present or became involved, what the parents did, what health professionals said or did and conclusions and evaluations of the events and actions narrated.

It was not always easy for parents to start the reports. However, after the first impact, though excited, they spoke with ease, showing great motivation to verbalize their stories. At the end of the interviews, relieved, it seemed that they thanked for the opportunity to share their experiences of suffering with someone who had been willing to hear them and record their words, sharing a reality lived and relived through the use of narrative. All interviews were tape-recorded and thereafter transcribed verbatim, resulting in transcripts. They included both words and other language features such as cries, intonations and voice tremors, sighs and silences. These have been used as a way of extending and strengthening the analysis.

The participant observation and open interviews held the triangulation of the methods in order to check, to compare and to situate the reliability of data. The two techniques were considered together, dialectically interacting in the composition of a whole, considering the interviews as an instrument to deepen the questions arose from the participant observation.

There were 21 meetings, 14 for observation (30 hours, 90 pages of field diary) and 7 for the interviews (8 hours, 117 pages transcribed), (Tables 1 and 2).

Data analysis

The primary data were analyzed by a model of knowledge linked to semiotics, described and called by Ginzburg (1986) *indiciário, a semiotic-based method*, where it is possible to reconstruct a reported event that one has not directly experienced by through the use of clues, signs, signals and evidences. When the signs are assembled they are submitted to comments and criticisms, separated and arranged to form large autonomous groups. Signs lend themselves to interpretation, because they carry semiotic values. Thus, the *indiciário or semiotic* model overcomes the simple reading of the signs or encoded signals because they are invested with meaning.

The analysis process began when the participant observation and the interviews were conducted. We applied *coding procedures* of qualitative analysis, common in the analysis of historical documents. These procedures include, at first, an *open coding,* processed by exhaustive semiotic reading, line by line of the field diary and the transcripts, in order to identify the signs, clues and evidences that indicated and formulate the data and, then, organization of the data according to the identified central ideas, themes and issues. The second procedure was a *focused coding*, based on topics already identified as of interest.

In the analysis, different important episodes were identified and arranged in chronological order that represented when they occurred in real time, making up a storyline or trajectory of the process of the parents' construction, organization and understanding of their children's prematurity. The narratives were created, taking also into account the elements of the speech or the so-called *discursivação,* in which characters and effects of time and space were introduced. The narratives were told from the viewpoint of the parents' present understanding, which would have an impact on their reconstructions of the past.

The family, considered as the initial social group is embedded in larger contexts: the society and the world around it, in which the family causes and, at the same time is affected. The stories have

Table 1. Participant Observation - Scenarios, number and length of each meeting, and number of pages of field diary

Participant Observation		
Families / Scenarios	A	L
	Number and Length of each Meeting	
SEH Outpatient Clinic	1 60 min	3 90min
Neurology	-----------	1 60 min
Housing	1 150 min	2 210 min
Family Meeting	1 240 min	--------
Birthday Party	1 240min	1 180 min
Church	1 180 min	1 240min
School	1 150 min	--------
TOTAL:	6 1020 min (17 h)	8 780 min (13h)
Total: 14 meetings; 30hours; 90 pages of daily field diary		

Table 2. Interviews – Number of inter views, number and length of meetings, scenarios, and number of the transcribed pages.

Families / Interviews	A			L			
	Au (father)	An (mother)	Total	J (father)	N (mother)	Total	Total
Number of interviews	1	1	2	1	1	2	4
Number of meetings	1	4	5	1	1	2	7
Length of meetings	2 hours	3 hours	5 hours	3 hours (both parents)		3 hours	8 hours
Scenarios		residence			residence		
Number of pages transcribed		72			45		117

brought these influences, through interpretative practices that emerged in the form of social expectations and ideological meanings.

This study was conducted within the norms set forth by the Declaration of Helsinki and approved by the Research Ethics Committee of the SEH, protocol number 000133 and ratified by the Research Ethics Committee of the Instituto Fernandes Figueira, Fiocruz, and protocol number 018/04.

RESULTS

From January to December 2001, 31 NBs with birth weight below 1000g were admitted to the NICU of SEH, RJ, of which 14 (45%) survived. Of these, two NBs and their families were selected according to the inclusion criteria. Data regarding gestation, delivery and demographics of the NBs, their stay in the NICU and follow-up visits after discharge are shown in Tables 3, 4 and 5. The results are presented as two narratives, the stories of A and L. The subjects were identified by the initial letter of their names, in underlining. What has been said by the families is written in quotes and in underlining. Four great themes were identified based on the analysis of the field diary and the transcripts that generated the narratives: healthcare, parents' stress, communication and social support network.

Story of A

Mother: An
Father: Au
Child: A

Table 3. Data regarding gestation, delivery and demographics of the newborns.

Gestation,delivery,and demographics of the newborns	A	L
Date of Birth	20:05:01	18:10:01
Mother: Age (years)	32	42
Educational level	primary education	primary education
Father: Age (years)	44	54
Educational level	primary education	primary education
Prenatal Care (number of visits)	10	6
Maternal Disease	chronic hypertension	chronic hypertension heart disease
Gestational Age (weeks)	28	28
Indication of the Gestation's Interruption	pré-eclampsia fetal distress	pré-eclampsia fetal distress
Way of Delivery	cesarean section	cesarean section
Apgar: First minute of life	7	8
Fifth minute of life	9	9
Gender	male	Female
Birth Weight	995g	785g
Postnatal Gestational Age (weeks and days)	32 4/7	31
Rating birth weight / postnatal gestational age	small for gestational age	small for gestational age

Table 4. Data regarding neonatal clinical history in the NICU.

Neonatal Clinical History in the NICU	A	L
Hyaline Membrane Disease	present	present
Length of Respiratory Support (days)		
Mechanical ventilation	16	-----
Continuous positive airway pressure (CPAP)	4	6
Oxygen Hood	10	5
Maximum FiO2 (%)	100	40
Bronchopulmonary Dysplasia	present	present
Sepsis	present	present
Antibiotical Therapy (days)	51	21
Intravascular Catheter (days)	22	0
Total Parenteral Nutrition (days)	18	23
Surgery	absent	Cryotherapy
Transfontanellar Ultrasound: at first week of life	normal	intra cranial hemorrhage III
at hospital discharge	normal	ventricular dilatation
Echocardiogram	ductus arteriosus	Normal
Ophtalmologist Avaliation	normal	retinopathy of prematurity III
Discharge Weight (grams)	2170	1900
Corrected Age (months and days)	1m 17d	1m 7d
Chronological Age/Length of Stay (months and days)	3m 7d	2m 9d

An has chronic hypertension. At 28 weeks gestation, she felt ill and went to the hospital. The baby hardly moved inside her womb. The doctor said that a cesarean section was indicated. An was sent to the obstetric center and when A was taken from her womb, she heard him cry. The pediatrician showed her the baby, quickly, and took him to the NICU. An only saw, as she remembers it, that A was ´very small, a little thing.´ The words that An use to refer to the first time she saw her baby translate the understanding she had of prematurity at that time: the fragility of her son.

On the next day, An asked Au to accompany her to the NICU since she would feel safer if he were around. At the NICU, An was shocked to see all the equipment

Table 5. Follow-up assistance and monitoring of children after discharge**.**

Follow-up Assistance After Discharge	A	L
Primary Healthcare Unit	yes	yes
SEH outpatient clinic	yes	yes
Ophthalmology	yes	yes
Neurology	yes	yes
Pulmonology	no	yes
Speech Therapy, Occupational Therapy and Psychology	no	up to four years old
Physiotherapy	no	yes
Education	literacy	absent
Current Age	5 9/12	5 4/12
Current weight	15 100grms	17 200grms
Disabilities	no	spastic cerebral palsy refractory seizures

connected to her son. She was afraid that touching him would hurt him. The next day, An went to the NICU alone. She picked A up for ´five short minutes´ and felt happy that he was fine but she was afraid to drop him because he ´was so tiny.´ The fragility that marked her since the first time she saw A, at birth, made her feel anguish.

After a few days, An was discharged from the hospital. She was afraid to leave A at the NICU, unsure of the kind of care he would receive. She would go to the hospital daily to visit A. One time she arrived at the NICU at the exact moment A was having a cardiopulmonary arrest. The doctor talked loudly, asking the nurses for ´things´ and the nurses were running back and forth. An saw a doctor insert a tube in A's throat, take it off and reintroduce it. She thought A had died. The nurse asked her to leave the NICU. After a few minutes, a doctor asked her to go back inside. A was ´full of tubes and equipments,´ but alive. The description of a cardiopulmonary arrest by a layperson causes great impact on professionals who treat this condition. The lack of understanding of what is going on, the perplexity and the suffering that her report transmits are intense.

Au understood that an incubator was necessary to keep A well but the image of the baby in it reminded him of the suffering of ´a person trapped in a barracks, unable to leave.´ Regarding this theme, Ayres (2005) states that the biotechnological sciences are the basis for the construction of the objectives of health-associated happiness. This author also mentions the importance of rebuilding the relations between biotechnological fundamentals, procedures and results and the values associated with happiness.

After two months, A showed clinical improvements and was transferred to the Intermediate Unit (IU). One of the worst moments for An was not finding A at the IU: he had been sent back to the NICU because his clinical condition worsened. Again she thought that her son had died. An said that she ´told A that he had to decide whether he wanted to live or not.´ An could not deal with the fear of A dying. This feeling is felt by most parents with NBs in NICUs. An also told A, as she recalls that ´ if he wanted to live, he would have to be normal, without sequelae.´ An had anticipated A to have sequelae, which may happen to premature NBs who survive.

An asked the doctors about A's condition. Au preferred to ask the nurses. He found it difficult to talk to the doctors because he probably felt he had an asymmetrical relationship with them, a situation where it is not possible for a discourse to flow. Au believed that ´the right information can ease a difficult situation; however, by not understanding what is going on, the layman supersizes the problem. At a certain point, without information, the layman loses control.´ At these times, for Au, ´it is necessary to believe in God above all else, it is necessary to trust.´ The religiousness of Au emerged as a mediator between the difficulty of talking to the doctors and the suffering he was going through. This is the spirituality that, according to Boff (2004:21) *unites, connects, reconnects and integrates, helping to compose the alternatives of a new civilization paradigm.*

Au trusted the treatment that was being given to A. For Au, ´when he enters a place where everything is dirty, one is talking bad about the place as is another one, things are not going well.´ Au translates what Boff (2004:18) points out as a malaise of civilization*: sloppiness, neglect, abandonment and carelessness*. In Au's own words, when he ´sees everyone well, working peacefully, he feels safety and confidence.´ Now, Au refers to what Boff (2004:33) calls *care, that is, an attitude of being engaged, showing preoccupation, responsibility and affective involvement towards another individual*. An would like to have had psychological support but she could not get it. An, then ´asked God for help´ as she usually did, because He always helped her, giving her ´strength to face the difficulties.´ She then went to the spiritist center where people talked to her and she could talk to people. An felt relieved. Faith, assures Parker (1996), gives sense to life and consolation and guidance in difficult and distressing situations.

A was finally discharged. An thought: ´My God, thank you so much for allowing my son to go home with me!´ ´Proud´ was how she reported feeling when she took A in her arms to leave the hospital. As she recalls, ´it felt like my son had been born at that moment because I left the hospital with him, not alone, so I then felt sure that he had been born in that moment.´ Preyde and Ardal (2003) describe feelings like An's felt, the emergence of her competence as a mother, the real moment her son was born to her, to her family and to the world.

At home, An ´changed A's clothes and put some clean, tiny clothes on him´ and put him ´lying in his little crib, like a small doll, like this, this petite size.´ Her words, in the diminutive, revealed the fragility with which she still characterized A.

An's family paid A a visit, and were ready to help Au and An. They had innumerous chores related to A: to take him to the Primary Healthcare Unit to be vaccinated and to the hospital for the follow-up visits which included seeing ophthalmologists, neurologists and pulmonologists.

An was sure that A was normal after one year, when she would ´lay him on his stomach in a certain way and shortly after he would be in another position, out of the sheets; she would then cover him again with the sheet and he would try hard to crawl out; he started to crawl and to sit perfectly well.´ Motor capacity was the sign that convinced An that A was normal and eased the stress associated with his birth.

A, today, a five year old boy is already learning to read and write. An does not forget the good or bad episodes, she ´organizes it all inside a file cabinet.´ Au says that ´A is a trophy´. The word trophy reminds us of something won with great effort and perseverance. A trophy, tangible proof of victory, is kept where it can be shown and in a way that the happiness that it represents is shared with those who see it. This is the idea that Au has and conveys to us regarding A. .

A represents the good outcome of extreme prematurity.

Story of L

Mother: N
Father: J
Child: L

N, a 41 year old woman has chronic hypertension and heart disease. At 19 weeks gestation, N felt ill and went to an Emergency Care Unit (ECU). She was diagnosed with preeclampsia and had to be admitted to an Intensive Care Unit (ICU). Arriving there, the fetus was suffering but still alive. The obstetrician told J that the likelihood of saving both, mother and child was dim and that ´J should start praying immediately if he had faith in God.´ J opened up in a dialogue with God and *through his religiousness, asked the supernatural power that helps the individual* (Boff, 2004:151).

After some clinical improvement, N left the ICU and was admitted to the infirmary. N and other pregnant women in similar conditions spent their time talking and knitting, identifying themselves in a network of social support.

After two months in hospital, at 28 weeks gestation, a cesarean section was indicated for maternal risk. L was born alive and after the first procedures, the pediatrician showed N the baby. N was shocked, she thought ´L was a very ugly child, she was not fully developed and she had the eyes of a frog.´ As N recalls, she would ask herself if ´that was a child.´

N asked to hold her child ´a little bit´ but that did not happen and L was soon taken to the NICU. N began building a bond with L, despite the initial rejection, but the team did not accede to her request, maybe because of the severity of L's condition.

J remained very watchful outside the obstetric ward. He only saw the hand of the pediatrician enveloped in a ´sheet.´ When he was told that that was his daughter, he thought to himself that her entire body could fit in his hand. He did not know that L would be born so tiny. Having a preterm infant is not among the expectations of any family. These are factors that produce anxiety in the parents of premature NBs (Eriksson and Pehrsson, 2005).

On the following day, N entered the NICU to meet her daughter. When she saw L, she thought, ´my God, this child is not going to live, she is going to die; the diaper, which was the only thing she had on, reached her neck.´ N was shocked when she saw her child in the incubator ´connected to all that equipment.´

N did not like to see the nurse's ´making holes in L´ for venipuncture. She thought her daughter was going through a lot of suffering and she suffered seeing her daughter suffer. According to reports by Gale et al (2004), this experience is stressful for the parents, who perceive and share the pain of their child. N asked: ´God, I very much want to keep my daughter, either she improves or you take her away from this suffering.´ N's request for God's intervention, according to Parker (1996), is the search for protection, which restitutes the harmonic order of life.

After a few days, N was discharged from the hospital. She did not understand how she was supposed to go home and leave her daughter in the NICU. She thought ´the nurses would not watch her daughter carefully at night.´ Uncertainty and fear arise when mother and child are separated, and these feelings are imbued by the loyalty of the mother towards the child.

N has good memories of her stay in the hospital. She misses the health team. N realized that the hospital caregivers had inter-subject attitudes and spaces supported by technology, but not limited to it, in according to references of Ayres (2005)

In the NICU, L had apnea and was ´connected to some equipment,´ as N recalls. The NICU team tried hard to explain to N what was happening to L in a way the she could understand. However, to N, L ´was already lazy because the equipment breathed for her; that is why she acted up, she was always acting up.´ There is evidence of N holding L responsible for not getting better, which was probably associated with her wish to get away from the organic process of the disease, to transfer the intercurrences that affected the child to the behavioral domain.

L had a respiratory arrest when her parents were present. At this moment, N made ´an agreement with God: God, if this child is meant to die, please let her die in the hospital, do not let me take her home.´ N's suffering was so intense while she watched L's suffering that she thought L's death would be more bearable.

L improved clinically and was transferred to the IU. N held L skin-to-skin and became familiar with handling her. N said: ´holding her skin-to-skin reassured me: if I did something wrong, the nurses would tell me.´ N noticed the benefits of the practice of *Kangaroo Care*, as reported by Lamy et al (2005).

L was discharged from the hospital. The pediatrician explained that N would have to give medications to her daughter and ´to observe her breathing during her sleep,´ among other advices. N left the hospital holding L, she was happy. At home, N and J ´managed to get the job done.´

L received additional care at the Primary Healthcare Unit and in the follow-up visits to outpatient, pulmonologist and neurologist clinics. The family needed to have the financial means, time and physical strength to take L to all of the follow-up visits. At eight months of age, L still needed support to sit up. A pediatrician told N that her child's development would be slower than what N expected. N would ´slowly find out for herself how L would turn out to be.´

L, today, a five year old girl, currently has paresis on her left side, needs support to walk, speaks only a few words, does not control her sphincters and has convulsions constantly. N ´cannot get herself to accept´ L's sequelae. However, the bond between L and her parents is very strong. J is always showing affection towards L: he hugs, kisses and caresses her. N shows her affection by dressing and combing her hair in a fashionable way, trying to keep the girl as close as possible to what is normal for her age.

N gets emotional when she looks at L and says, in her own words, that despite all the difficulties she had to face, her daughter is ´a gift from God.´

DISCUSSION

The identified four great themes, healthcare, parents' stress, communication and support network will be discussed above.

Healthcare

The NBs and their mothers received care in a public, tertiary teaching hospital. They had timely access to effective obstetric and neonatal interventions, which probably contributed to their favorable outcomes.

However, some aspects of the care given to these families were not suitable.

The first contact between the mothers and their NBs in the delivery room was quick, undermining the process of formation of mother-NB bond. Despite the severity of the NB's condition, after the baby is clinically stable, the health team should be instructed to allow the mother to look at and to touch her child, even if only for a short time (Wigert et al, 2006).

The first time the parents entered the NICU, they were alone. This occasion was traumatic to everyone. To the family, the NICU is an unknown place where the technological apparatus is, at first, threatening. In this first contact, there should be a member of the health team with the parents, capable of explaining the baby's condition and the treatment that is being given. If proper information is supplied by the health team to the parents, they will eventually consider technology something that ensures the safety of their children (Strathern, 1995). This is the importance of the connection between biotechnological advances and happiness, mentioned by Ayres (2005).

Parents' stress

The birth of a preterm infant causes suffering to the parents, which often translates into anger, guilt, anxiety, sadness and fear (Ericksson and Pehrsson, 2005). In our study, this kind of stress was constant and present at different times with the fear of death emerging as one peculiar form.

Fear of mother's death due to eclampsia was important during gestation and delivery, subsiding gradually. Fear of child's death was high when the child was born and peaked when the parents saw the NB for the first time in the NICU and when the child had cardiopulmonary arrest. The parents felt what Polatscheck (2006) calls despair and fear of losing a child that looks fragile, born without resources, and under so much suffering. When the children were discharged, the fear faded away since they had already survived the most difficult stage. Fear of child's death returned intensely when the parents, once at home, found themselves to be the *caregivers*. As they felt, over time, that they were actually capable of caring for their child, the fear diminished. However, it never faded. A secret expectation that death might still occur remained as a mark of a period of great suffering.

In the delivery room, mothers were alarmed when they first saw their children, their fragility translating their premature condition. Experiences such as these are described by Goodman (2005) as a reality check, the stage when parents become involved with their preterm children. In situations such as the ones seen here, the healthcare team should mediate the parents-infant bonding. This attitude is still incipient in teams working in NICUs. The implementation of continuing educational programs is necessary to train professionals who work in this field and make them aware of this need.

In the NICU, An and N saw their children have a cardiopulmonary arrest. Cardiopulmonary resuscitation requires full and undivided attention from intensive care pediatricians, oriented towards the actions that need to be fast and precise: there is a life to be saved. Handling of the child and instruments is the center of the universe. The question is: would it be possible to focus on the technical procedures and, at the same time, minimize family's pain? Humanization of medical care is undeniably necessary, but how could it be inserted in critical occasions, without nullifying the actions that need to be taken in those occasions? This is a very fine line.

The NICU-to-home transition and the anticipation of morbidities caused anxiety to the parents. An slowly calmed down as A developed properly but N remained anxious since L's development would be slower than N had expected. The situation that N and J faced is reported by authors such as Raina et al (2005): it is difficult to look after a child with special needs, especially when there are functional limitations and a possibility of a lifelong dependence. Regarding this theme, Polatscheck (2006: 667) states: *A child never fits perfectly into the model the parents imagined, always surprising to some degree. Nothing is given, everything needs to be built. Each organism that is born is a new subject to be constructed, unpredictable, just like everything associated with human life.*

The family of a child discharged from a NICU needs psychologist and social work assistance. To achieve this, the public healthcare system needs to be aware of this demand and organize itself to provide the necessary assistance to these families.

Communication

Mainly in the NICU environment, communication was both in a negative and in a positive way depending on the occasion and the people involved. Proper communication between the health team and parents minimized the families' stress and made them feel protected, as mentioned in the literature (Caprara and Rodrigues 2004). Some parents identified the nurses as the first ones they should ask for information regarding their children. Nurses had a calming effect on the parents, which helps to further build the parent-infant bond (Kowalski et al., 2006).

While the NBs were in the NICU, the communication between parents and health team was also inadequate and created a gap between them. The language barrier impaired the interaction, the relation was asymmetrical. The medical discourse prevailed and the doctor-patient relationship was focused on the doctor. According to literature reports, the doctor represented for the parents a strange, mysterious and distant universe (Silva, 2002).

The medical team needs to become aware, through lectures and meetings with professionals from the humanities, including bioethics, of the need of improving communication with the parents, to enhance doctor-patient relationship, breaking the monologue characteristic of the technoscientific rhetoric. The doctor needs to reduce doctor-patient asymmetry, focusing on the patient and not only on the disease.

Social Support Network

The nuclear and extended families, friends, people who experienced similar difficulties at some point, religion and the health team were the components of the social support network.

The children of this study are being raised in an environment where there is love and caring among its members, protective factors for their development. The mothers gain strength from the support given by the fathers. The fathers, when requested, despite the traditional role of the *providing father*, behaved like the idealized *new father*, participating and showing affection (Bustamante and Trad, 2005). Relatives' support was especially important during the first days of the child being home, after discharge. The extended family represented what authors like Carvalho (2003) called the *condition of endurance* of the low-income Brazilian family, the possibility of maximizing income, support, affection and relations to obtain health.

In the infermary, the pregnant women mobilized themselves, clumped together and identified with their peers in a network of social support that enabled them, as Braga (2006) states, to transform the reality of which they were both object and subject.

Spirituality emerged in all phases of the narratives as a very powerful tool that helped the families endure the suffering they were experiencing. During gestation and childbirth, they ask God for strength to bear hardships and for ability to accept suffering. In the NICU, the prayers were for the Divine Power to assume responsibility for a possible negative outcome, transforming the doctors into His instruments. At hospital discharge, the families thanked God for being able to go home with their babies. Today, they thank God for the lives of their children, asking Him for protection against any evil that can still happen to them. Parker (1996) mentions that religiousness emerges when life is on the line, to help understand the world as it is.

Cardoso (1997) points out that, although medicine has undergone vast changes over time, attitudes toward disease remained almost unchanged. Today, faith in scientific knowledge coexists with faith in the effectiveness of magic, prayers, healing hands and herbs. For Cardoso (1997), this is because diseases persist in being the home of our ghosts; they remind us of our finitude and integrate human historicity.

Conclusion

Gestational hypertension was a risk factor for extreme prematurity, prolonged neonatal intensive care and separation of the NBs from their families. The narrative brought to debate relevant issues that only emerged because of the conditions in which the observations and interviews occurred: in a comfortable environment, with respect and empathy between the interviewer and the interviewees, and with plenty of time available, circumstances that are characteristic of the qualitative methodology.

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