

## THE PARTICIPATION OF PARENTS IN THE CARE OF PREMATURE CHILDREN IN A NEONATAL UNIT: MEANINGS ATTRIBUTED BY THE HEALTH TEAM<sup>1</sup>

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*This qualitative study aims to identify and analyze the meanings the health team attributes to the parents' participation in the care of premature children hospitalized at a public hospital. Data were recorded and collected through semi-structured interviews performed with 23 professionals. The results show that parents' participation in the care of these children is still in an initial stage at the hospital's neonatal unit. However, there is interest from the health team to implement it because its importance is recognized in improving the clinical stability, the growth and development process of premature children. In addition to allowing for mother-child interaction and affective bonding, it prepares the mother for the child's discharge. The presence of the mother helps the nursing team by giving maternal care to the hospitalized child. On the other hand, the parents' presence interferes in the environment of the neonatal unit. It affects the work dynamics and creates insecurity among team workers, who feel supervised. Besides, there is concern regarding hospital infection. Thus, in accordance with other studies from different countries, these meanings entail reflections on the need to base the premature care in terms of collectively building a care philosophy that restores concepts of human rights, citizenship, bonding and mother-child attachment, pediatric psychology and also expands the concept of training for a participative health education.*

**DESCRIPTORS:** infant, newborn; infant, premature; infant, low birth weight; family; neonatal nursing

## PARTICIPACIÓN DE MADRES/PADRES EN EL CUIDADO DEL NIÑO PREMATURO EN LA UNIDAD NEONATAL: SIGNIFICADOS ATRIBUIDOS POR EL EQUIPO DE SALUD

*El estudio tiene como objetivo identificar y analizar los significados atribuidos por el equipo de salud con relación a la participación de la madre/padre en el cuidado del niño prematuro hospitalizado en un hospital público. Se trata de un estudio con enfoque cualitativo. Los datos fueron recolectados a través de la entrevista semi-estructurada y grabada de 23 profesionales. Los resultados mostraron que, aún esta participación es incipiente dentro de la unidad neonatal hospitalaria, no obstante existe interés por parte del equipo de salud en implementarla, reconociendo su importancia al favorecer en la estabilidad clínica del prematuro y en su proceso de crecimiento y desarrollo; permitiendo de esta forma, la interacción madre-hijo y el establecimiento del vínculo afectivo, así como el entrenamiento materno para la futura alta. Se percibió que la madre ayuda al equipo de enfermería brindado cuidados al niño y realizando cuidados propios de su función materna. Por otro lado, la presencia de los padres modifica el ambiente dentro de la unidad neonatal, pues interfiere con la dinámica de trabajo, genera inseguridad en el equipo por sentirse fiscalizado, así mismo, existe la preocupación por infecciones hospitalarias. Estas situaciones en conformidad con otros estudios en diversos países, nos llevan a reflexionar sobre la necesidad de fundamentar la asistencia al prematuro hacia la construcción colectiva de una filosofía de cuidado que rescate conceptos con relación a los derechos humanos, ciudadanía, vínculo y apego madre-hijo, psicología pediátrica y de esta forma, ampliar el concepto de entrenamiento en educación participativa en salud.*

**DESCRIPTORES:** recién nacido; prematuro; recién nacido de bajo peso; familia; enfermería neonatal

## PARTICIPAÇÃO DAS MÃES/PAIS NO CUIDADO AO FILHO PREMATURO EM UNIDADE NEONATAL: SIGNIFICADOS ATRIBUÍDOS PELA EQUIPE DE SAÚDE

*Esse estudo tem como objetivo identificar e analisar os significados atribuídos pela equipe de saúde acerca da participação da mãe/pais no cuidado ao filho prematuro hospitalizado em um hospital público. Trata-se de um estudo com delineamento na abordagem qualitativa. Os dados foram coletados através de entrevista semi-estruturada e gravada de 23 profissionais. Os resultados mostraram que esta participação ainda é incipiente na unidade neonatal do hospital, mas há interesse da equipe de saúde em implementá-la, reconhecendo a sua importância ao favorecer a estabilidade clínica do prematuro e seu processo de crescimento e desenvolvimento, possibilitar a interação mãe-filho e o estabelecimento do vínculo afetivo, bem como o treinamento materno para a alta do filho. Percebemos ainda, que a mãe ajuda a enfermagem nos cuidados do filho hospitalizado, executando cuidados de maternagem. Por outro lado, a presença dos pais modifica o ambiente da unidade neonatal, pois interfere com a dinâmica do trabalho, gera insegurança na equipe que se sente fiscalizada e há preocupação com as infecções hospitalares. Assim, esses significados em consonância com outros estudos em diferentes países, nos levam refletir na necessidade de fundamentar a assistência ao prematuro em termos de construir coletivamente uma filosofia de cuidado que recupere conceitos sobre direitos humanos, cidadania, vínculo e apego mãe-filho, psicologia pediátrica e ampliar o conceito de treinamento para a educação participativa em saúde.*

**DESCRIPTORES:** recém-nascido; prematuro; recém-nascido de baixo-peso; família; enfermagem neonatal

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## INTRODUCTION

Technological advances in neonatal care have increased the survival of younger and younger children, weighing between 500 and 700g, who can survive at the gestational age of 24 weeks<sup>(1)</sup>.

Besides premature infants' biological vulnerability and low birth weight, the risks caused by the therapeutic process at neonatal intensive care units, the use of highly complex procedures and the long hospitalization period turn these babies more susceptible to infections and other diseases. These situations increase the family's social and emotional costs even more, as they involve great human suffering and, thus, turn premature birth and low birth weight into a public health problem<sup>(2)</sup>.

Historically, child care has been the mother's responsibility. However, in the hospitalization process of sick children, the family has been excluded from care, a conduct justified by the knowledge available at each moment in history. Before the Second World War, the mother was separated from the premature infant, as the mother who used to breastfeed her premature child started to be considered as a threat to the child's fragility and as a source of infections. Hence, she was impeded to maintain contact and could only see her child through windows<sup>(2)</sup>. After the Second World War, the effects of maternal separation and/or privation on the child's development and personality<sup>(3-4)</sup> started to be studied, and the traditional care model, centered on the sick baby, started to be transformed into a new model that allows for the mother's/family's participation in care, based on new philosophies, concepts and care models<sup>(2)</sup>.

However, despite this new model, advances in literature and the development of human rights legislation for children, in our reality, the situation of premature infants has not changed a lot. Nowadays, in most Mexican hospital, the parents'/family's visit to the newborns is still restricted and controlled by rigid standards, while the mother's participation in care for the premature baby is still limited. The separation between the mothers and families and the premature infants attended in the hospitals of San Luis Potosí, which is still present at most neonatal units, despite knowledge proving the advantages of their participation in care, and despite the transformations and innovations in many services in Brazil and other countries, motivated us to carry out a study about this theme.

Considering that health professionals are potential agents of change in health services, the

realization of this study is justified in order to identify their perception about the parents' insertion in care for their child at neonatal units. Thus, we highlight the importance of knowledge production in Mexico, with a view to contributing to the transformation of care.

This study aims to identify and analyze the meanings of mothers'/fathers' participation in care for their premature hospitalized child, attributed by the health team of a neonatal unit in San Luis Potosí, Mexico.

## METHODOLOGY

We carried out a descriptive and qualitative study. This approach was chosen because it is the most appropriate to discover and understand the meanings of human actions and relations, which statistics do not reveal<sup>(5)</sup>.

The study was carried out at a neonatal unit of a public hospital in the city of San Luis Potosí, Mexico. This care institution is funded by the federal and state governments and care is paid for by clients. It is a regional, secondary care hospital, with some tertiary-level functions, and attends to the rural and urban low-income and middle class populations from the city, from San Luis Potosí State and from other neighboring states. Ethical considerations are based on article 3 of the Mexican General Health Law, and on article 100 of the same Law with respect to research involving human beings. The project was approved by the institution's Ethics and Research Committee.

Study participants were 23 health team professionals, nine of whom had a teaching diploma in nursing, while one was a general nurse (N1... N10); four nursing aids (NA1... NA4); one emeritus neonatologist, two adjunct neonatologists and one neonatologist specialized in early neurostimulation (NE1... NE4), two resident pediatricians (RP1 and RP2) and two social workers (SW1 and SW2), who accepted to participate in the recorded interview and signed the informed consent term.

Data were collected through semistructured interviews, which contained the interviewee's identification data and were guided by three open questions: Tell me what you think about the mother's participation in care for her premature child at a neonatal unit. ¿How does the mother participate in care for her premature child at this neonatal unit? ¿What do you suggest to favor maternal participation at the neonatal unit? The interviews were held at the

hospital, between September 2003 and September 2004, during the interviewees' work shift, and took an average of 45 minutes.

The theoretical reference framework was constituted by the approach of premature care transformations, historical landmarks for care and the mother's participation in care for the premature infant at the neonatal unit. The method used was qualitative, thematic content analysis. The presence of certain themes indicates the motivations, opinions, attitudes, values, beliefs and tendencies, that is, the reference values and behavioral models present in discourse. Based on the three operational steps, i.e. pre-analysis, exploration of the material and treatment and interpretation of the obtained results, we discovered the units of meaning that constituted this communication<sup>(5)</sup>.

## RESULTS

All health professionals consider that it is important for the mother to participate in care for her premature child at neonatal units, and some highlight that the father should also participate:

*... I think that yes, that it is very important that the fathers come, well, the mother, but I think the father too... (N4)*

*... the fathers' participation is essential in the newborn's evolution, for a long time we talked about the mother-child dyad, now it's about the mother-father-child triad. (NE1)*

We apprehended the following meanings: The mother's/father's presence favors the premature infant's clinical stability and growth and development process; Participation allows for mother-child interaction and affective bonding; The mother is trained for the child's discharge; The mother helps the nurse to take care of the hospitalized child and The maternal presence of the parents modifies the environment at the unit.

The mothers'/fathers' presence favors the premature infant's clinical stability and growth and development process

Health professionals highlight that the parents' stimulus in care for the premature child leads to greater weight gain, favoring the child's growth and contributing to the premature baby's neurological development:

*... when the mother takes care of the baby, the baby grows better and faster and, so, that is the first part, when the mother takes care... to leave the hospital faster... (NE4)*

*... yes, there are advantages, some children stay hospitalized for 3 months... they are more reactive and their internal psychology already starts to open up and, at this moment, they are already aware of who is beside them, and that is an advancement... bringing the mother close to touch him and this contact is very important for his neurological formation... (RP2)*

Furthermore, it is highlighted that proximity to the mother/father offers positive stimuli to the premature infant's stability and clinical evolution, reduces hospitalization time and decreases the baby's new hospitalizations, thus minimizing care costs:

*... and the second reason is not to be hospitalized again when they leave, to evolve better when they go home... we have recent data in which we (observe) that the time in hospital is shortened... between 10 and 15%... (NE4)*

*... spending is less (\$)... (NA3)*

Participation allows for mother-child interaction and affective bonding

All interviewees highlight the aspect of the relation between the premature infant and the parents, especially the mother. This interaction occurs through tactile (touching and caressing) and auditive stimuli (talking and singing). Hence, this frequent contact and the relationship between mother and child are important for the establishment of affective bonding:

*... so as to get to know her child... another important thing is for her to touch him... we have seen that the fact of touching him, of stimulating him, of talking to him, is very useful for the baby's further formation... this stimulus by the mother is very important, to touch him, to caress him, to talk to him, to sing to him... (RP2)*

*... this interaction between the mother and the infant because the mother passes tranquility, passes good vibration, caresses him, gives him, the baby should not be separated from the mother, bonding with the mother starts there, at that moment, with caresses... the two can enter equally at the intensive care unit, father and mother who touch him, who caress him, even when he is receiving ventilation... (NE3)*

The team, mainly the doctors, mention some effects of a non harmonious mother/father-child relation and of badly established bonding, such as child violence and emotional privation:

*... the first (problem) is the syndrome of the mistreated child, this first consequence is as if it were an abandonment, they leave him and the mother does not come back; when they have him (at home) he is subject to mistreatment... The second (problem) is the abandonment of feeding, that they don't give him food – poor thing, and the third (problem) is the abandonment of psychomotor development, that he does not evolve adequately because they had no early contact... (NE4)*

### The mother is trained for her child's discharge

According to the interviewees, the parents want to take care of their child, but they are afraid because of his small size and the technological apparatus involved in care:

*... very often, the fathers participate slowly, and sometimes they go and see them (baby) but it scares them because the baby is very small... they don't want to hold the baby's little hand, they don't want to hurt or fracture them... (N8)*

*... I think that yes, it's a limiting factor – the technology – because when the mothers see them full of machines, they don't want to touch them either, they're afraid, they think that something's gonna happen to them... (N2)*

When interacting with the health team, the parents seek information about the child's condition, care and the prevision of discharge. The parents' questions are mainly directed at the nurses, but it is the doctor who gives information about the diagnosis.

*... there is nothing written, only the resident or the medical head can give information, because there were several problems, so it was formalized... because, in fact, saying nothing more than "he's stable"; "he's delicate"; "it's very serious", not making prognoses "that the baby's very small", "that it depends a lot on the baby if he gets discharged or not" and "that it's very individual for each baby" I say it like this "maybe a month, a month and a half, it depends on the weight gain and, for them, 1g is very important... (N1)*

*... it are they (nurses) who have most contact with training the fathers because sometimes one (doctor) does not give them anything else but general information and one orients them to the nurse and she's the one who is there more about the details... if you need someone, it will better be a nurse, she needs to be dedicated to a patient so as to be able to give attention to the father... (NE2)*

The care provided by the mother at the neonatal unit is related to a formal or informal training process. The mothers learn about care, especially feeding and, depending on the child's clinical status, they provide some special care, it depends on them at home. This training is mainly given by the nurse.

*... I believe the nurse participates more, because it are nurses who teach them more, such as how to breastfeed them, how to remove the nipple from the baby's mouth, and so these ladies feel more secure too... (RP1)*

*... participate in feeding, because if the infant can already be breastfed or fed by suction... when changing diapers, clearing the genitals... and if the baby is discharged with medication, as this will also be part of the orientation she needs to receive, what type of medication she'll take home and also the vaccination schedule she has to take, that would be a separate piece of information, extraordinary. (N5)*

Social workers locate the mother who attends the neonatal unit and provide food, accommodation and transport aid if necessary.

*... if it's due to a lack of money, we contact her and reach an agreement, a deal (with the parents), we give financial support (\$), we support her here, we look for donations for transport tickets and explain the family member not to be concerned, that we will provide support in money or transport tickets... (SW1)*

*... the parents leave, and leave the babies for 8 or even 15 days and doctor X gets annoyed: "they no longer leave me, that this lady (mother) does not come... just look at what happens with this lady who is abandoning this boy" and with any team member or with the social worker, who is trying to localize them (the parents) to come, even if two times per week... (NA5)*

### The mother helps the nurse to take care of the hospitalized child

Nursing shares care related to the early stimulation and feeding of the premature baby with the mother. Some nurses perceive this participation as a help that reduces the work overload:

*... for early stimulation, the doctor comes every day in the morning, she also gives them exercises, so that they (the parents) also exercise their mouth so as to start stimulating, now resides that we (nurses) reinforce them in case of any doubt because they ask us anyway... how to stimulate them, how to establish contact, they start to talk to them, the baby is more reactive, he's hearing the voices, they move, this helps him a lot, because even if we (the nurses) wanted to talk to them, or stimulate all of them, sometimes we don't have enough time... and they (mothers) help us if we have a lot of work, because that is also an advantage, they help us to feed him... (N6)*

*... sometimes there's a work overload for nursing and the fact that the mothers help us to give the bottle and knows how to give it, this gives the nurses time to continue care... (N8)*

### The maternal presence of the parents modifies the environment at the unit

Despite acknowledging the importance of the parents' insertion in the neonatal unit, the interviewees also appoint a disadvantage, because the parents' presence modifies the environment. This aspect is particularly mentioned by nursing, stating that the parents interfere in the work dynamics and do not focus care on the child:

*... the only disadvantage I'd see is that the mother is not prepared for it, that she does not receive training before she gets contact...because it happens that the mother arrives and*

that, instead of watching the baby, she looks at what we are doing, the machines, and she observes other things ... (N5)

... there is a problem, that they (parents) want to interfere outside visiting hours, that is the problem we face in neonatology, for example, we arrive after 6 or before 4, which is the time when we are only taking care of the children, feed them, deliver care, so that at 4:30 pm the parents are there, and that is the problem, that they want to interfere at any time... some babies are really delicate and we cannot take care of them because the parents are there and do not let us deliver proper care... (NA2)

This situation creates insecurity about the realization of the procedures in front of the parents and even fear of possible questionings or denouncements by the clients:

... and, in some situations, the mother may not like what she (the nurse) is doing with another or even with her own baby, and that's when denouncements come up (to the government or human rights); she is entitled to, but it is a limiting factor for us to perform as we constantly do at the service... (N8)

The parents' education level also affects the relation with the nurse, who feels intimidated by questions about the baby when asked by more prepared persons, who may even be impeded from entering the neonatal unit. Other difficulties relate to communication with less educated parents, who do not understand the orientations they receive:

... the mothers ask little, it are better prepared people who ask more, once a man asked me about the Apgar, so I said to myself, "oh man, why does he come here and talks to me about the Apgar" and, well, he was a teacher. And I think that, when prepared people come, we stop, including me, and sometimes we don't even let them pass because we decide "no, that one asks too many questions." Some time ago, a man asked about oxygen saturation, that is, can you imagine! And my colleagues did not let him enter because he asked questions, but the majority does not ask and, if they ask, the question is ¿have you given a bath already? or ¿have you changed the diaper already?... (NA1)

... it's harder with people coming from the rural zone, they don't understand what we are saying... (NA2)

Special attention is given to the team's lack of preparation to deal with the mother and the family at the unit, as the professionals' training in general is focused on physiopathology. Hence, some interviewees mention the need for recycling, although the courses ministered in-service do not allow for wide participation by the team:

... we use her (early stimulation doctor) for support because she's the most involved, she has taken courses, she's prepared, we (residents) have almost no preparation, not in this specific area, only what we see, the focus is much more directed at the physiopathological aspect and early stimulation... (RP1)

... one (nurse) is not accustomed to chat with anyone, one creates a routine, from home to work and pure routine. It's really difficult here (in-service training), everyone adapts things to his schedule, for example those from the morning shift take courses, because yes, they take them (courses), in fact I don't even come, because they give the courses in their schedule... there's a lot of training missing for us at night... (NA4)

Some professionals are still concerned about infections generated by allowing visitors' entry into the neonatal unit. On the other hand, this rule is refuted by a doctor who demonstrates updated knowledge about this problem:

... when I started to work in neo (neonatal unit), we were prohibited to let the parents enter, only we (nurses) and the doctors were there and there was less infection ... that is, they saw the babies through the window... because, as these people do not live near, they come from far, they're staying at the hostel, in the street ... so it's important that, the mother comes in, she washes her hands, but it's not the same thing...the neonatal unit is a delicate room because of the kind of patient! (emphatically); so I tell them, wash your hands very well, put on the gown and get in, I leave and I make sure that they wash themselves well, but the other day the mother sees me and says "here's that annoying one, I'd better not get in" (into the neonatal unit)...(NA1)

... that was questioned at first, everybody said that, when the parents entered, infections would increase and that scared us, and that is what happened, nothing happens...of course, according to the rules, when the mother or the father has an infection, theoretically they can't (enter), but if they wash their hands, use the gown – in the USA they no longer use gowns- but we do use the gown, when he (the baby) is ill, because something (protective) to the mother and nothing happens... and all serious infection peaks that occur, they're not because of the parents, they're due to other things... (NE4)

## DISCUSSION

All interviewees indicate the importance of the mothers' and fathers' participation in care for the premature baby at neonatal units, in line with previous studies<sup>(6-7)</sup> and recommendations for its implantation at neonatal units, starting from intensive care until discharge from hospital<sup>(8-9)</sup>.

The benefits of the mothers' and fathers' participation are widely acknowledged, including the child's weight gain, decreased hospitalization time<sup>(6)</sup>, affecting the baby's behavioral and cognitive conducts and the modeling of brain architecture<sup>(7)</sup> and beneficial in the treatment and recovery of hospitalized children<sup>(10)</sup>. The results of controlled studies have also

demonstrated these clinical effects, such as reduced ventilation dependence, improved weight gain, earlier start of non nutritive suckling, self-regulation, neurobehavioral improvement, decreased hospitalization time and lower care costs<sup>(9)</sup>.

In general, research about the family's insertion in care for the hospitalized child has focused on maternal participation. This is understandable as, historically, women have assumed the role as responsible for family care.

A study about paternal experiences at a pediatric intensive care unit apprehended that, when participating in care for hospitalized children with congenital heart diseases, the father lived this experience and perceived himself as decision maker, as support to his wife and child, and tried to conciliate this experience with his daily work reality. These meanings reflected the man's role in society as in possession of power and responsible for the family's maintenance<sup>(11)</sup>.

Transformations in social gender relations have been evidenced. Nowadays, we know that fathers can adopt maternal behaviors, due to their capacity to regressively identify with the baby<sup>(4)</sup>.

Nurses do not fill up the space next to the child and fathers are entitled to be present during their child's hospitalization<sup>(11)</sup>.

In child care, the family-centered care model has been emphasized. It involves a set of philosophies, principles and practices, which put the family at the center of care, understanding it as the primary strength and support resource, which is important for decision making in child care<sup>(12)</sup>.

Health professionals should offer consistent support and care quality standards, based on respect, responsibility and the family's needs<sup>(9)</sup>.

With respect to the meanings the interviewees attributed to the mothers'/fathers' participation at the neonatal unit as favoring the infant's clinical stability and growth and development process, we observe that they are in accordance with those attributed by nurses involved in care for the hospitalized child, who have been interviewed in some other studies<sup>(6, 10)</sup>.

A quantitative study of nurses at some hospitals and maternities in São Paulo City found that all interviewees reported that it is important for mothers to participate in care for preterm newborns, indicating that they provide the first stimuli for the children's beneficial and fast evolution. The children present greater weight gain and recover faster, which supports their physical, mental and affective

development. The separation of the mother-child binomial was mentioned as a factor that affects the child's physical and mental growth. The nurses mentioned weight gain and the possible reduction of hospitalization time as advantages<sup>(6)</sup>.

This aspect is also observed in a qualitative study that analyzed the meaning of extending the mothers' participation in care at a pediatric rooming-in unit of a public hospital in Cascavel, Paraná, according to nursing professionals. The interviewees emphasized that this participation offers great benefits, including the child's faster recovery<sup>(10)</sup>.

With respect to the meaning attributed to the mothers'/fathers' participation as favoring interaction and the establishment of mother-child bonding, studies and theories sustain the importance of the mother and father relating with the child, with a view to the development of a healthy personality and the formation of a solid base for mother-child bonding and attachment<sup>(3)</sup>.

The importance of mother-child interaction has been highlighted in order to prevent the damage caused by early separation, which can be more or less severe, ranging from the mistreated child syndrome to abandonment, and due to its relevance for the establishment of bonding and attachment<sup>(3,9,13)</sup>.

Warmth, intimacy and a constant relation with the mother or another person replacing her on a permanent basis are considered essential for the newborn's and young child's mental health. This care avoids the maternal privation process<sup>(3)</sup>.

We believe that the care the mother gives to her child and the fathers' visits to the neonatal unit correspond to the bond the parents want to establish with their child, through their proximity, thus trying to transmit their love to their baby. In this sense, according to the mothers, when they are present, their children feel more protected, secure, confident and cared for<sup>(10)</sup>.

The family should be present at all neonatal units, particularly those attending a high-risk clientele, considering the increasing survival of more immature babies who require long hospitalization periods. In this sense, it is highlighted that family-centered care rests on the understanding that, for the child, the family constitutes the first force and support, and that it offers benefits to the child, the family and institutions, reducing low birth weight and preterm birth rates in perinatal health. Hence, the use of the family-centered care model is recommended, based on this family's well-being from the prenatal period to birth, hospitalization, follow-up and support after discharge<sup>(12-13)</sup>.

During her participation in care for the premature child, the mother is trained at the neonatal unit. Thus, she receives information and advice about hygiene and feeding care. Specialists and researchers have discussed the relevance of the advice the mothers/fathers receive during the premature child's stay at the neonatal unit, presenting recommendations and guidelines for its systematic development<sup>(6,9-10,12-13)</sup>.

In this study, nurses are mentioned as key professionals in training the parents. The mother is trained and delivers maternal care to her premature child, especially those related to feeding, at the mother's breast or through a formula.

However, this training and information is created from the professionals' position in the technical and social division of work. Hence, when the doctor informs the mother/parents about the child's condition, the diagnosis, treatment and clinical evolution, this is because they have taken control of the work process at the neonatal unit as a whole. In nursing work, the nurse coordinates, guides and supervises the nursing staff and other employees, as well as the organization of the environment<sup>(14)</sup>.

In the context of the technical and social division of work, the parents play a passive role towards the professionals and they may not be experiencing their participation as a right<sup>(15)</sup>, but as a set of actions imposed by health professionals.

We believe that Mexican neonatal services are gradually acknowledging the importance of this training with a view to the continuation of care at the baby's home. However, at the neonatal unit under study, the mothers/fathers receive generic advice, depending on the baby's disease, often at the moment of discharge.

The planning of discharge should include the parents' education, who can be involved as soon as the baby is admitted, starting their participation in care for the child at the neonatal unit. One of the positive effects this entails is the acquisition of skills to continue care at home<sup>(13)</sup>.

Reflecting about this new paradigm and in line with current recommendations, we believe that premature infants, when they leave the neonatal unit, are still in risk situations. These children face greater risk of dying or sequelae and, after discharge, may need some special care which the parents have to learn.

The way this participation has been occurring, i.e. without the mother's participation in decision making, does not contribute to the construction of shared care among mothers and nurses, distances them and strengthens the execution of fragmented

care, divided in parts, according to the value attributed to each care act, as the mother participates in more domestic care, which are less valued because they pose less intellectual requirements<sup>(10)</sup>.

In this relation with the health team, the mothers can either help or interfere, depending on their attitude towards these situations. Although they are considered as collaborative agents in work, depending on the moments and routine activities at the service, the parents' presence at the neonatal unit modifies the environment and, in certain situations, the interviewees expressed that they interfere in the dynamics of work, mainly when procedures such as medication, clinical tests and other more complex treatment procedures are carried out. According to the nurses, the mothers should help without being invasive<sup>(10)</sup>. This means that the mothers/fathers can remain at the unit without breaking service rules, with the team, especially nursing professionals, establishing times for the parents' access to the neonatal unit.

This reveals a duality in the interviewees' perception. They consider it is relevant for the parents to participate, but the nurse can be one of the main barriers against this permanence, because the nurses relieve that the parents are a source of stress and use their valuable time<sup>(8)</sup>; hence, the parents collaborate but sometimes also interfere in work.

The nurse's concerns about infections caused by the parents' and relatives' entry into the neonatal unit lack a more elaborate scientific foundation. The transformations in care for the premature infant brought about by the incorporation of psychological questions into care practice have led to the parents' more active insertion in care for their child, including care at intensive care units<sup>(2)</sup>. Other family members, who used to be impeded from getting into neonatal units, started to related with the infant during his long hospitalization, whenever necessary and individually planned. Results of microbiological and epidemiological research evidence that this practice has not caused any increase in hospital infections. Hence, the foundations of infection prophylaxis have been reviewed, and the focus of restrictive isolation measures moved to the use of discardable materials and procedures to disinfect equipment and caregivers' hands.

## FINAL CONSIDERATIONS

The mothers'/fathers' participation at the hospital is still incipient, but the health team is

interested in implementing it, acknowledging its importance because it favors the premature infant's clinical stability and growth and development process and also allows for mother-child interaction and the establishment of affective bonding, as well as maternal training for the child's discharge.

In participating, the mother helps nursing in care for the hospitalized child, providing maternal care. On the other hand, the parents' presence modifies the environment at the neonatal unit, as it interferes in the dynamics of work and creates insecurity in the team, which feels controlled and concerned about hospital infections.

Another advancement in care at the neonatal unit we studied in Mexico refers to the fact that some professionals also indicated the importance of the father's insertion in care for the premature child. This makes us think of changes in the mother's role as the only caregiver for the family's health, and that these transformations derive from the new care demands posed by the organization of current family systems, in combination with changes in the social context.

Therefore, there is an urgent need to implant permanent education of the neonatal team, beyond educational techniques, also including contents about care focused on development; attachment and affective bonding between mother, child and family; interpersonal relation, client welcoming, among others, with a view to improving the mother's and the family's training for care delivery at home. Moreover, there is a need for a broader understanding of the preparation for the baby's discharge, with a view to following the babies' growth, their adequate and healthy development and a participatory health education process.

Hence, we need to think of transformations, however, starting from the professionals' own reflections, trying to look at the reality of the subjects who are experiencing these situations – the parents of the baby hospitalized at the neonatal unit, who also have something to say. The family's participation in care for the premature baby has to be inserted into the institutional philosophy, a gap appointed by the interviewees.

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