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Veröffentlichungsversion / Published Version

Zeitschriftenartikel / journal article

#### Empfohlene Zitierung / Suggested Citation:

Cabeça, L. P. F., & Sousa, F. G. M. d. (2017). Dimensions qualifying for communication of difficult news in neonatal intensive care unit. *Revista de Pesquisa: Cuidado é Fundamental Online*, 9(1), 37-50. <https://doi.org/10.9789/2175-5361.2017.v9i1.37-50>

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## Dimensões qualificadoras para a comunicação de notícias difíceis na unidade de terapia intensiva neonatal

Dimensions qualifying for communication of difficult news in neonatal intensive care unit

Dimensiones para la comunicaci3n de califican noticias difcil en unidad de cuidados intensivos neonatal

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Article drawn from the Master's Thesis entitled: The molds for the communication of difficult news in the NICU: present meanings, reflections for the future, defended by the graduate program in nursing at Federal University of Maranhao (UFMA) and linked to the Study Group of and Family Health Study in children and adolescents (GEPSEFCA) of the UFMA Nursing Department.

### How to quote this article:

Cabeça LPF; Sousa FGM. Dimensions qualifying for communication of difficult news in neonatal intensive care unit. Rev Fund Care Online. 2017 jan/mar; 9(1):37-50. DOI: <http://dx.doi.org/10.9789/2175-5361.2017.v9i1.37-50>

### ABSTRACT

**Objective:** Understanding the qualifying dimensions for communication of difficult news in the neonatal intensive care unit. **Method:** Descriptive exploratory study, qualitative, from the thematic analysis. 10 mothers of newborns and 14 professionals were research subjects. **Results:** The use of strategies in helper/for the communication of difficult news in the NICU were revealed in the speeches of the research participants as facilitators in the process of interaction between professionals, mothers and families, allowing this type of communication, reduce the suffering of those involved, favoring support and support to the mother and family and extend security to overcome difficulties and challenges. **Conclusion:** The requirement of relational, interpersonal and communication skills in professional, from an expanded care and care that goes beyond the prevalent as technical and technological dimension in intensive care make it necessary perspective.

**Descriptors:** Nursing. Communication. Difficult news. Neonatal Intensive Care Unit.

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## RESUMO

**Objetivo:** Compreender dimensões qualificadoras para a comunicação de notícias difíceis em Unidade de Terapia Intensiva Neonatal. **Método:** Estudo exploratório descritivo, qualitativo apoiado pela Análise Temática. Foram sujeitos de pesquisa 10 mães de recém-nascidos e 14 profissionais da terapia intensiva neonatal. **Resultados:** A utilização de estratégias auxiliadoras no/para a comunicação das notícias difíceis na UTIN foram reveladas nas falas dos participantes da investigação como facilitadoras para o processo de interação entre profissionais, mães e famílias, permitindo nesse tipo de comunicação, reduzir o sofrimento dos envolvidos, favorecer apoio e suporte à mãe e à família e ampliar segurança para ultrapassar dificuldades e desafios. **Conclusão:** os resultados sugerem competências relacionais, interpessoais e comunicacionais a partir de uma perspectiva ampliada do cuidado que ultrapassa a dimensão técnica e tecnológica tão prevalentes em terapia intensiva.

**Descritores:** Enfermagem. Comunicação. Notícias difíceis. Unidade de Terapia Intensiva Neonatal.

## RESUMEN

**Objetivo:** La comprensión de las dimensiones de calificación para la comunicación de noticias difíciles en la unidad de cuidados intensivos neonatales. **Método:** A, qualitativa, el análisis temático descriptivo del estudio exploratorio. **Resultados:** El uso de estrategias de ayudante/para la comunicación de noticias difíciles en la UCIN se revela en los discursos de los participantes en la investigación como facilitadores en el proceso de interacción entre los profesionales, las madres y las familias, lo que permite este tipo de comunicación, reducir el sufrimiento de los involucrados, favoreciendo soporte y apoyo a la madre y la familia y ampliar la seguridad para superar las dificultades y desafíos. **Conclusión:** The requirement of relational, interpersonal and communication skills in professional, from an expanded care and care that goes beyond the prevalent as technical and technological dimension in intensive care make it necessary perspective.

**Descriptores:** Enfermería. Comunicación. Noticias Difícil. Unidad de Cuidados Intensivos Neonatales.

## INTRODUCTION

The Neonatal Intensive Care Unit (NICU) environment is characterized by constant expectations of emergency situations, where the newborn (NB) will be constantly subjected to invasive procedures and subject to risks of complications and sudden changes in their general state. Given this, it is common for family members to be addressed by healthcare professionals with information that can be translated as bad news.<sup>1</sup> Therefore, the diagnosis, the risk of death, disability, the worsening of the condition, prognoses, among other situations, are part of the therapeutic process and care in NICUs. However, expressing such situations to the family is a complex phenomenon, difficult and often embarrassing, though unexceptional, while it is revealed as a task/action/attitude of the professionals in the care process.

As it appears in Leitao and Araújo,<sup>2</sup> the difficult news includes situations that pose a threat to life, to personal, family and social welfare, the physical, social and emotional consequences that they entail. Thus, the term difficult news means any information conveyed to the families of patients

entailing some negative change in life.<sup>3</sup> Under this perspective, assess how bad the news is, not the content of the message itself, but the experience or expectation with this type of message, as well as the form of the notice, the time when it will be done and the consequences that it may produce.<sup>4</sup>

Concomitant to these issues, the Ministry of Health instituted in 2003, the National Policy of Humanization, whose structuring axis is the horizontality of the relationship, the bond and the listener sensitive strategies to break with the model of biologist attention to health and appreciation of the other as a subject of rights. Thus, the advances in care processes directly reflect on changes in the value of life, when they are considered moral, ethical values and human,<sup>5</sup> condition that makes us rethink the process of news communication difficult in the context of the high-risk newborn care.

It is understood that the professionals are the first recipients of difficult news, as are those who access this information through examination results, therapy and clinical course of the disease. In this perspective, the pros need to handle this information in short time and report them to the family. In addition to issues relating to diseases, the professionals face everyday situations that are actually difficult news, as, for example, accidental extubation, loss of venous access, delay in the process of therapeutic support, newborn death, lack of medications, reduction of staff as a result of shortages, leaves and vacation, breaking ties with the team and with the family, in addition to emotional and social conditions of this. Therefore, professional experience high load of difficult news. These are situations that reveal the emphasis of the National Policy on Humanization translated as a product of real transformations in subjects and services<sup>6</sup>, to suggest producing transformer environments of healthcare practices, as well as individual and collective.

Then, experiencing everyday situations in the NICU, highly intensified as treating children, and generate suffering for the family and for professionals, associated with increasing levels of illness, are characterized as extreme. As for the latter, it is noteworthy that the experiences of the professionals in the process of taking care of the high risk newborn (NB) of care, for the most part, maintained in their intimacy and are rarely shared in institutional spaces, restricting them as a rule, the trust with close friends. At the convergence of the above referred to, the professionals are challenged in their skills and their individual responsibilities in isolated<sup>7,31</sup> and, thus, experience those limits in private, having a peculiar way of experiencing them.

Another highlight in this issue, little staff training for difficult news communication coupled with the emotional support of families, which can cause silences, sudden communication diagnostic, prognostic, therapeutic procedures, among others, with serious damage to the therapeutic relationship between professionals and family. Such circumstances trigger reactions of weakening and

uncertainty permeated the meanings attributed to the moments experienced both by professionals and families.

Thus, the communication of difficult news, professionals are actors who act having regard to their own perceptions, conceptions and, therefore, define and determine intentions and practices. Therefore, the starting point of this investigation with the rationality of the actors, as well as to contexts, situations and events that emerge from the process of illness of the newborn in NICU and care practices involving the NB, mother and family.

Based on these considerations, the object of this research delimits by the theme of difficult news in the context of the NICU and the experiences of the researcher as a clinical nurse at this level of health care and on all changes in defense of humanization of practices and the appreciation of life that involves both processes and attitudes such as work management. They are life experiences/experiences that led to the elaboration of the following questions: What relational and communicational skills qualify and humanize the process of communicating difficultness in the neonatal intensive care unit?

Being concerned with the theme of difficult news in NICUs is therefore closer to the proposal of the National Policy of Humanization, being understood that "humanize is able to provide concrete changes in all those involved in health practices, changes that are occurring both the subjects and the work management."<sup>6:48</sup> Moreover, it is an issue that involves the interaction, or, on the other hand, the decoupling between the healing and caring. It is also an issue that approximates the meanings of care ethics, responsibility, respect and dignity, characterized as important players in the humane care.

Given the above, this study aimed to understand, from the verbalization of mothers and health professionals of a Neonatal Intensive Care Unit, the dimensions generating for the communication of difficult news in the Neonatal Intensive Care Unit.

## METHOD

This is an exploratory and descriptive study with a qualitative approach carried out in the Neonatology Service at the University Hospital of the Federal University of Maranhão (HUUFMA) Unit, Mother and Child Unit in São Luis - MA, Brazil, which is part of the Hospital Complex of this institution.

Study participants were those directly involved with the communication phenomenon of difficult news, professional NICU and mothers of newborns hospitalized there. In this sense were defined the following inclusion criteria: Being a professional in the NICU, regardless of category, with experience in the service of six months or more, being a NB mother aged 18 years or over, who is or has experienced the hospitalization of infants in the NICU; be in physical,

emotional and psychological to establish a dialog and a partner with good verbalization.

Inductively, data collection was started by mothers, and then by professionals of the Neonatology Service. The research participants were 10 mothers of newborns at high risk and 14 professionals who provide care to this clientele in the NICU (5 nurses, 2 physiotherapists, 3 medical and 4 nursing technicians). These characteristics define the subject as a heterogeneous group, an important condition for qualitative research that prioritizes this condition for the validation process of the collected information.

To ensure anonymity, the identification of survey participants was made through the letter M (initial letter of the word mother), followed by a digit corresponding to order of interviews (M 1...M 10) and P (initial letter of the word professional), followed by the figure corresponding to the order of interviews (P 11...P 24).

The mothers survey participants were young people aged between 18 and 27 years (70%) while 30% were equal to or greater than 30 years being 38 the higher age among them. They had a stable marital situation and 50% were inserted into the labor market with formal employment, 25% were students and 25% were housewives. As to the type of delivery the percentages were the same for Cesarean and normal (50% each), gestational age between 27 and 41 weeks and presented as problems during pregnancy and childbirth that indicated the diagnosis of hospitalization at the NICU: Disease Specific Hypertensive Pregnancy (HDP), rupture of membranes, prematurity (PMT), premature detachment of the placenta (DPP), premature labor (TPP), Oligohydramnios, urinary tract infection (UTI), severe anoxia and congenital malformations.

Among the professionals interviewed, three were medical, two physical therapists, four nursing techniques and five nurses distributed in the age ranges between 27 and 52 years, with service time in the NICU between two and 30 years and elapsed time of the undergraduate course between three and 32 years, therefore, with significant professional experience. All professionals of higher level had specialization and/or residence in Neonatology.

The interviews with the mothers and professionals have been actioned by means of an invitation personally and, not being followed no strict order to invite them. It took into account the adjustment of schedules and dates, with a view to availability as well as the expression of interest for research. It is worth mentioning that there was good receptivity on the part of mothers and professionals, expressed both in readiness to accept the invitation, as the availability to begin the interview. Of the invitations made by me, only one professional denied their participation in research.

Some interviews needed to be rescheduled. Two of them due to clinical worsening of the newborn and a due to the demand of complications in the NICU not allowing the professional time for the interview. In addition, two interviews took place in two phases due to the emotional state of the

mothers. In this last aspect, the researcher allotted a time and provided immediate professional support to mothers with a partnership with the unit psychologist. The interviews were conducted in different places, in order to preserve the privacy of participants, such as the family care (16 interviews), the home doctor (4 interviews) and room service for the little ear's test at the outpatient follow-up to the NICU (4 interviews), located on the premises of the institution.

To conduct the data collection a non-structured or open interview was used to more broadly explore the investigation. For the interviews with the mothers we used the following request to motivate their verbalization: Tell me how it was for you receiving the bad news about your child while they were at the NICU? To achieve higher density and further exploring the phenomenon under investigation, circular questions, such as were used: as has been said? Tell us more about it. Can you talk a little more about this?

The data collection process with the professionals followed the same structure but with different questions: Talk about their experiences in the communication of difficult news in the NICU. In the same way, we used the circular questions for higher density and deepening of the object under study such as: In your opinion, what qualifies the communication of difficult news? What strategies should be used by professionals in the communication of difficult news?

The research project was submitted, first, the head of a Neonatal Intensive Care and supervision and the Nursing Division of HUUFMA. Afterwards it was referred to the Scientific Committee (COMIC) of HUUFMA for analysis and opinion, with protocol number 001821/2013-90 on 19 April 2013 and was approved with the number of opinion 40/2013. Then it was inserted on the platform for analysis of the Ethics Committee on August 30, 2013, being approved in the opinion of the number 405,099, on September 24, 2013. For this research, all ethical principles determined by Resolution 466/2012 were respected. After agreement of the participants to participate in the study, they read and signed the consent form Clarified in two copies, becoming one with the researcher and the other with the participants.

The data collection process was initiated in November 2013 and completed in January 2014, when the quality and density of information obtained enabled the development of the theme and the scope of the research objective.

The interviews were conducted by the researcher and recorded in MP3 player, with the prior consent of the interviewee, i.e., preceded by signing the Informed Consent Form (ICF). After each interview, the researcher was the transcript, as short period of time. Then a printed copy of the interview to each participant so that they validate content thus providing the data reliability criterion was delivered. This validation is very important for the enrichment of the data, because in addition to clarify doubts that have arisen over the transcripts, the interviewees were able to change and/or add something to the content previously entered.

The data were interpreted and analyzed on the basis of the Thematic Analysis proposed by Minayo,<sup>8,316</sup> which "consists in discovering the meaning cores that compose a communication whose presence or frequency means something to the analytic objective pursued."

The thematic analysis is divided into three steps:<sup>8</sup> the first is the pre-analysis which consists in the initial selection of material to be analyzed according to the objectives of the study in search of information that indicates the path of the final interpretation. This phase is divided into sub-phases: Reading: at this stage, the data collected in the interviews were transcribed, organized, read and reread until it was possible to the impregnation of its contents. Constituted *corpus of research* 24 (twenty-four) interviews are defined on the basis of the criteria of validity, among which the comprehensiveness, representativeness, homogeneity and relevance. In the completeness, it tried to cover all the points raised in the interviews, aiming to check if participants had answered the questions posed. The representativeness sought to understand the speech of the subjects containing essential characteristics of the target universe. In relation to the uniformity it was that in all the questions asked to the interviewees appeared the main theme of the study and the relevance in search of the documents reviewed were adequate to meet the objectives of the work. At this pre-analytic stage, determine the meaning cores (keywords or phrases), context unit (the delimitation of the context of understanding the registration unit), the excerpts, the type of categorization and the theoretical concepts that will guide the analysis. At this stage of the process of analysis, 258 units of meaning emerged. The second stage involved the exploration of the material where the raw data were worked from the understanding of the text and with the units of meaning. Initially it proceeded to the selection of units of meaning in the text (a word, a speech, a theme), according to what was established in the pre-analysis. At this stage revealed the themes that were selected after several readings and re-readings and that had similarities. The third step is the treatment of the results obtained and interpretation, the moment in which the researcher deepens the analysis of themes from inferences, interpretations and emerging evidence in cases investigated.

## RESULTS

For this publication will be presented one of the constructed and developed themes for the Master's Thesis linked to Program Graduate Nursing of the Federal University of Maranhao and the Group of Study and Research in Health, Child and Adolescent (GEPSCFA) entitled "frames of communication difficult news in NICU: this way, reflections for the future." This theme was appointed qualifying dimensions for the communication of difficult news in the Neonatal Intensive Care Unit defined from the organization of 258 units of meaning and gave rise to two sub-themes:



Auxiliary strategies/for Communicating Difficult News in the Neonatal Intensive Care Unit and Structural Elements for Communication Difficult News in the Neonatal Intensive Care Unit, which helped us to understand the factors that shape the relationship of these to the news media difficult in the context of neonatal intensive care.

*Theme:* Qualifying dimensions for the communication of difficult news in the Neonatal Intensive Care Unit.

To envision the Qualifying Dimensions for Communication Difficult News, it is considered that parents, especially mothers of newborns admitted to the ICU are in emotional stress and potential crisis.<sup>9</sup> In addition to the unfamiliar environment, mothers and other family members become dependent professionals to be able to handle the situation and to become familiar with the condition and the child's care. Therefore, the communication between mothers, families and professionals is an essential dimension of care in neonatal intensive care units.

From this perspective, the understanding of the communication of difficult news in the NICU was revealed by the necessity of qualifying dimensions and as an essential tool for the care. The communication in the NICU was gradually taking shape as a requirement in the process of care aimed at reducing the stress and anxiety of the mother and the family and as a strategy for improving relations between mothers, families and professionals. Among the dimensions, generating both mothers and professionals, pointed out that the communication in the NICU needs to be at the same time, comforting and respectful; that promotes trust and that professionals in preliminary point to difficult news announcement, are sensitive to identify patterns of behavior, the conditions and knowledge of mothers and families about the disease and the situation of children and to collaborate in promoting support network to support the mother, family and child care.

*Sub-theme:* Auxiliary Strategies/for Communicating Difficult News in the Neonatal Intensive Care Unit.

The use of auxiliary strategies for the communication of difficult news in the NICU were revealed in the speeches of the research participants as facilitators in the process of interaction between professionals, mothers and families, allowing this type of communication, reduce the suffering of those involved, favoring support and support to the mother and family and extend security to overcome difficulties and challenges.

Communicate to the mother and the family about the critical state of a newborn pre-term and low birth weight was as complex task and that raises the use of support mechanisms. Among the strategies revealed, the survey prior knowledge of family members about the actual situation of the child in the NICU, their emotional conditions, and the beginning of the dialog, by means of a judicious approach,

were mentioned as key strategies for the communication process of difficult news:

*"I try to first identify myself for the family when announcing a difficult notice. I try to start a dialog to approach the family of the newborn and then start to speak of the possibilities of this baby [...] I start talking in detail the characteristics of him then start to speak of the difficult news. [...] I see the environment in which the mother is, their condition, so that I can prepare it to start this dialog." (P 15)*

*"In the first approach of giving a bad news, I wonder what she already knows about your baby and, sometimes, she herself has already said about the condition of her child. I see in her eyes that I have to go slowly, which I cannot say that the baby has a poor prognosis. [...] say anything depending on what I perceive in her countenance. I see a lot of the emotional state of the mother." (P 18)*

According to the reports, for the communication of difficult news, there is a part of the professionals a care directed to the receiver, which in most cases are the mothers. In a general way the protocols for communicating difficult news are conformed in steps that bring together the surroundings, the patient's perception, communication, empathy, and the strategy. Among the existing guidelines highlights the Protocol SPIKES, which describes a teaching the steps for communicating news difficult, among which the preparation of professionals for the meeting, the patient's perception and the invitation for dialog.<sup>3</sup> are general guidelines on how to systematize the communication of difficult news, which are in line with the attitudes revealed in this research.

These findings are also relevant, because this attitude of caution regarding who will receive the news is fundamental for the relationships and interactions among future professionals, mother and family and for continuity of care.

But, in actuality, the development of skills and abilities for communication of difficult news has been underestimated and the practice in this field is based on advice and in the implementation of protocols.<sup>10</sup> On the other hand, protocols are detailed road closed and, therefore, do not meet the needs of different regions and cultures, but can point the legitimation of competences to the communicative process. However, they represent a framework for organizing and enhancing the communication enabling autonomy and leadership to the family in decision-making processes of illness and treatment of the child.<sup>11</sup>

There is now a consensus that there is more than one proper way to communicate difficult news, because people and their needs differ, so there are no ready-made recipes for the communication of difficult news.<sup>12:166</sup> For the author,<sup>12</sup> it is up to professionals to rely methodologies able to achieve various possibilities, given the need for a dual activity, which

on the one hand could deal with unique issues of doctor-patient relationship and the other needs of the patient and their family. As a result, the author suggests some theoretical support in the area of communication competence, but above all that communication is understood as a meeting intergroup involving differences of power, authority and autonomy and at the same time, proximity, reciprocity, commitment and respect that goes beyond the normative approach of a protocol. Therefore, it seems necessary to seek creative and innovative strategies for communicating difficult news, using as a starting point the revision of the compelling practices and hierarchy of health services and professional relations with users and clients.

Discuss a little more about the auxiliary strategies to communicate news difficult, there is a need of parents being aided by professionals at the first visit to the Son in the NICU for this moment is experienced in a less traumatic.<sup>13</sup> One of the reasons that justify this intervention is based on the premise that the loss of the experience of the birth of a child healthy is highly stressful and traumatic for the parents, because they had an expectation that the birth of the child would be a great party, a condition denied by the current reality. Parents, especially mothers, to develop relationships with the professionals work as strategies to manage the experience and that the team is crucial to the normalization of that experience.<sup>14</sup> Thus, it is essential that the team assisting the family can provide opportunities, mediate and facilitate the meeting of the mother with the son as revealed in the speech:

*“When I arrived in the ICU for the first time the nurse said I had to wash my hands, I could touch the baby, spend all day in the ICU and various other information about the problem. This person was nice to me, she knew how to explain [...]. I had service with the psychologist and social worker.” (M 4)*

That points one of the strategies in communicating difficult news – the humanization-configured as a base that sustains the care, come and appreciate the people in their individuality and needs. Humanization is present when the Professional is able to exercise and look with relational skills, and human communication that transforms the care as something peculiar, because it involves soul and sensibility.<sup>15</sup>

The support and support to family members are fundamental to prevent illnesses process in search of acceptance, forming, strengthening or restoring the child in the NICU. So that to receive the family professional must provide minimum conditions of comfort, trying to respond to the concerns, providing simple explanations about the State of health<sup>16</sup>, are attitudes that reflect and influence in communication and in relations during the hospitalization.

The support group has configured itself as important strategy to meet the needs of information and emotional

support to families of patients admitted to NICU.<sup>17</sup> This support is crucial in the process of coping, in search of acceptance, forming, strengthening or restoration of the child. For this to happen the professional to receive the family, should offer minimum comfort conditions, trying to respond to parents' concerns by offering simple explanations of health status, seeking to emphasize the child rather than equipment or disease.<sup>16</sup> In this regard, the statements reveal the support of professionals and demonstrates how such attitudes are relevant and representative for those who receive or communicate difficult news:

*“The ICU psychologist talked to me because I was so angry I was kind of on edge, I cry for nothing, cried for all the fact to see my daughter in that situation.” (M 2)*

*“I worry as those families will receive difficult news. [...] and you have to know who is this family. I believe that because we are an interdisciplinary team should be able to reach a consensus on how this news will be given. See doctors talking to parents about the pathology of the baby, which can happen, which led to complications, i.e., try to take the news in a more flexible manner.” (P 16)*

In recognition and appreciation of this support as a result of contact between the professional and the familiar and through information, Neonatology services, including the site where the research was conducted, has invested in the realization of individual service strategy and for clarification of doubts (Clarifying Questions). These visits promote communication space for family members to share their feelings and answer your questions about the child's health conditions. In the group of speeches, the respondents reveal the existence of those moments, and reinforce the importance of these spaces:

*“At the meeting answering questions that each question you want to know, was also told that he had an infection and that the medication time was 45 days, the antibiotic.” (M 2)*

*“We go in stages, i.e. we don't arrive and dump everything about the baby at once. There is a whole context, steps that we reach and that there comes a time that we invite to have a more detailed conversation about the baby's prognosis. This happens at a time with the psychologist, with a social worker, in a lounge reserved for the family.” (P 23)*

The existence of a network of social support (family, friends and professionals) was characterized as an important strategy for the communication process of difficult news. The support network, through compassion, solidarity and confidence allows the strengthening of family members contributing positively to the confrontation of the situation.<sup>18</sup>

This recommendation can be extended to all the moments that involve communications that affect family members psychologically and/or key aspects of their life.<sup>19</sup> Therefore, the social support network is a significant factor of protection to those who experience the process of difficult news:

*“I think if I didn't have it here (nursing technician) I would not have had support and I would have totally lost direction. Here are many human, friendly people, even mother's! I don't think she realized that it was a moment of very good help, came a good comfort.” (M 8)*

*“Often, when the mother finds it difficult to assimilate what is happening it is important to call the family. Sometimes, the father or other family member has a better understanding and are the people who will help when they are home. [...] If we tried to include the family, prepare this family [...] this news would be interpreted not as bad.” (P 16)*

The research of Gooding et al.,<sup>20</sup> whose family support and interlaces theme care centered on family in NICU, points out that the support of a family to other families can be a valuable source of information, hope and support, in particular when contact is made with families whose children have or have had similar condition. Emphasize that contributions of this strategy are positive for the confrontation of the disease process, treatment and hospitalization. Another strategy advocated by the authors to the education of families with regard to the environment of the NICU, the baby's conditions, the grief, the experience in the NICU and the transition to high, because they reduce stress and increase the confidence of the family. In that respect, the importance of common areas for parents as a positive strategy for the emotional state of the same, because they enable support and relief from loneliness by sharing experiences.<sup>21</sup>

Among the strategies, providing daily bulletins and the daily tracking of the relatives for a professional reference, were highlighted as expectations of mothers and professionals, who understand how tools for the communication of information on the clinical conditions of the child, as well as the need and resource scheduling surgical and therapeutic, because it would facilitate the understanding and the daily monitoring of the child by the mother and the family:

*“It's important to let the mother know what's really going on with their child. An opinion should be given to the family, as a routine. Mothers often only know that their child is worse or better when seeking information. This is very bad. There should be a daily newsletter so that they (mothers) would be knowing all, day after day. I think that, upon receiving a hard shock news wouldn't be so strong. The daily bulletin, in my opinion, is a preparation [...]. If the mother is accompanying daily and getting*

*daily information everything would be easier. [...] I think it should be part of the service routine.” (P 16)*

*“Maybe what we're needing is a person, so that mothers can find this person in particular and not a different doctor each day. Having a doctor monitoring the mother is a reference. This reference to the mother is important. The complications are of the attending physician, the mothers must know from attending what occurs at that moment, but I'm finding that mothers are left very alone. So it's important to have a daily monitoring.” (P 18)*

Designate a person as a reference and support for the family proved to be highly effective because these people help parents feel less stressed, more informed, confident and prepared for the process of hospitalization and discharge.<sup>22</sup> For the authors, this strategy is coated in benefits for the staff of the NICU and for the quality of care in this environment.

In the management of child care in the NICU parents must receive frequent information about the condition of the child, including the realistic prognosis based on the clinical condition and capabilities of neonatal care.<sup>20</sup> The authors<sup>20</sup> argue that to keep parents informed and involved in the NICU is important to doing the *rounds* as a strategy to help them better understand the condition of the child and to share their own perspectives on the evolution of the child. This increases the satisfaction of parents, live as long as the team dedicated attention both to the child and the family, and, above all, they feel respected by the professionals.

In the speech of the participants the contents of religiosity were unveiled as a strong strategy for both the communication and the confrontation of difficult news. The belief is able to assign a meaning to the suffering regardless of religion, provides confidence in the caretaker and generates hope in recovery of health.<sup>18</sup> is a strategy that can help the actors involved in the daily life of the NICU:

*“I know what only God can do for her. I would talk to God because he could and can comfort me, strengthen and give my baby, which gave me until today and, to counteract what the doctor told me today she has six years and seven months.” (M 1)*

*“I base myself on that I live, I'm Christian, I talk, and talk a lot of the love of God for mothers and what God has planned for each of us and all events can be a path. I mean that they can get their religiosity to strengthen themselves.” (P 16)*

The feeling of insecurity in the face of the unknown, the fear of death and uncertainty about the future, strengthen the strategy of religiosity and spirituality in the context of the NICU. Faith in God allows the development of hope and



prospects for better days and foster resignation,<sup>23</sup> therefore, minimizing the impact of difficult news. Otherwise, religiosity and spirituality are features that should be encouraged in health services contribute to the dynamics of daily work and how interpersonal relations enhancers and mediate in the health-disease process.<sup>23,24</sup>

Religiosity and spirituality allow greater control over the lives and unpredictability of the living process, so guys are dealing with greater tranquility. Otherwise, that is, the absence of such a tool is a generator of anguish and anxiety.<sup>25</sup> Thus, believe and put control of the facts and events in the hands of God's factor that reduces stress and anxiety. From this perspective, religiosity and spirituality help give meaning to the experience of illness and death and show up as drivers of behaviors to a State of adaptation and adjustment and renewal of energy for those involved to identify resources and learn to deal with the situations. It is, therefore, strategies to support mothers and families and professionals who deal with situations involving life and death.

The difficult news for being a complex task, professionals in the NICU where research was conducted to reveal the development of interdisciplinary work emerging from the need to share responsibility for taking decisions in relation to the joint communication of difficult News:

*"Working in a team, each giving their contribution to this moment. Reflect together how we should give this news, what's the best way, involving all of the team, so that we can live better and also being able to take this news of a better way for parents who need this support." (P 11)*

*"Trying to assemble wheels of conversations, exposing and trying to choose a better way. I know that there is a better way written, something already made, a Protocol, a recipe, so the group discussions lead to questions, making the professional get a posture that didn't have before." (P 15)*

The difficult news are multidimensional acts that should involve a multidisciplinary team.<sup>26</sup> Accordingly, the author emphasizes that the teamwork only happens when it is the product of a set of principles, such as: respect, understanding, appreciation of the role of the other, trust, and communication mechanisms for *feedback* and evaluation. And as continuous and systematic process to ensure fair, consistent information access, without contradictions and ambiguities, it is necessary that all healthcare professionals work as a team being essential to the process of effective communication.

The difficult news become arguably more complex when they involve. It is known also that the health professional in their daily lives, dealing with situations of suffering, and death as a constant element present. In case of death, the communication professionals must understand and make with the expressions of feelings of family members leading the communication of human form, because the way to communicate the death

influences directly in the process of acceptance of the death of the newborn on the part of family members.<sup>27</sup> In this respect, the strategies revealed in order to develop the communication process of death in the context of the NICU, involves a process to allow the reception of relatives:

*"We try to bring the parents, to the extent that they feel ready for it or get the desire to be here in recent times. We've had experiences of mothers who put the baby on her lap, and can participate in the entire process." (P 23)*

Given the sensitivity of this moment, the preference for non-verbal communication before death situations was described by professionals as relevant strategy, which allows in addition to supporting the feeling of being supported:

*"When it comes to death in ICU I can't talk much with the parents, I'm more of a hugger." (P 11)*

*"Looking for leaving the family to develop the process of grief, mourning with the family and, if there's no accompanying family, get more time next, offer a chair. My posture is to be next to them, maybe a touch, a cuddle. To preserve the moment of grief. [...] have professionals who are on the bench trying to keep quiet, others are family-side trying to mourn, comfort." (P 20)*

The health care professional in contact with suffering in its various dimensions lives and experiences conflicts about how to position themselves in the face of pain.<sup>28</sup> Given facts and difficulties suppress emotions and ambivalent States where permeate awareness approach, empathy and detachment. As much pain as suffering<sup>29</sup> lies in the field of technology and ethics and as such suggests physical interfaces, psychic, social, spiritual and, sometimes, emerging care of health professionals. In this respect, the suffering gives rise to compassion which means "solidarity action" translated into empathy<sup>29,296</sup> and also respect to consider the person not simply as body, but "as a whole one, a knot of relationships,"<sup>29,296</sup> appears to be the full exercise of citizenship in the context of care and health services where the action of caring promotes possibilities and capacities in which those involved are constructed as people. In this sense, the personal experiences of the professionals with difficult news, were included as facilitators to conduct this process in the NICU:

*"Each acts in a way to announce the difficult news. When you don't have a sense of how it should be done, if you act the way the person, what brought it home, that is, how do you deal with the difficult news out of the hospital. I act out there the way I act here, because I didn't have another preparation." (P 14)*

*“With my experience every single one of these years, and have already received some difficult news, I’ve been there, and I know I need to look for the speaker, and come and explain. I think you’re suffering from the other makes when you’ve been through some suffering. My concept is that you feel more, have empathy with the suffering of others, when you’ve been through it. When you never went through these situations is very difficult to be empathetic with any person or situation. Not that you’re insensitive, but because it’s passed and feel better the problem of another.” (P 21)*

The pros use their personal and professional experiences, and these lead to judgment with regard to the decision in the best way and time to inform mothers about the complications and clinical changes of the newborn. In addition, learning on news communication management difficult, most of the time, informally, through the observation of more experienced professionals, that is, the professionals learn from your practice, regardless of guidelines.<sup>30</sup> When the professional is more experienced, skilled, accustomed to dealing with situations of gravity with the customer, covers the familiar with looks and gestures which demonstrate more easily to convey difficult news. Less experienced practitioners already have more difficulty, but attempt to serve as support right now.<sup>1</sup>

Living with the pain, loss and death bring to the professional experience of its internal processes, its fragility, vulnerability, fears and uncertainties, which are not always shared. Thus, the health professional, contact the suffering in its various dimensions, associated with stress situations, need attention.<sup>31</sup> the search for support and psychological care are auxiliary strategies for professionals:

*“We work to give life and it’s difficult when you can’t and the patient will be aggravated and people feeling unable didn’t care to reverse the condition. [...] We go to work, preparing to not feel so much. I do analysis to help me on these points. It has helped me a lot.” (P 24)*

For both, the difficult news is for professionals interviewed a very complex and delicate experience that demand of professional involvement and responsibilities. In this context, some statements revealed the need to create living space for discussion among professionals about the problems and difficulties faced in the difficult news reporting process, as support strategy and professional reception:

*“Should have a space for discussion, to see how the team is mostly for new people who are coming.” (P 12)*

*“Assembling wheels of conversations, exposing and trying to choose a better way. [...] the group discussions lead to questions, making the professional get a posture that didn’t have before.” (P 15)*

*“It can’t just be a talk to professionals about the subject, but there has to be a continuous work to work with professionals about emotional issues arising from the work in the ICU. A job to take care of who cares.” (P 24)*

In the process of taking care of newborns and their families, it is necessary to mean life overcoming technical assignments and develop the ability to understand the human being in their life stories, their experiences, feelings and values. In this sense, the communication protocols would fail in the hands of professionals who understand the communication as an accessory, minimizing your relational character.<sup>29</sup> This statement is important because in the therapeutic relationship and communication of difficult news professionals consider only the verbal component of communication. However, the non-verbal communication such as facial expressions, movements, gestures, posture, distance and physical contact are important strategies and work qualifying or not. In this sense, the best way to communicate a difficult news would be sitting at the side of the receiver (which this investigation is almost always the mother) and rather reserved and deprived of noise and intervention of other people.

*Sub-theme 2: Structural elements for reporting difficult news in the Neonatal Intensive Care Unit*

This sub-theme was composed of 143 units of meaning that emerged from the interviewees’ statements and that contextualize the relevance of elements that structure the communication of difficult news in neonatal intensive care. In this way, the lines highlighted issues for research participants, are important in the context of the experiences of who communicates and who receives such news: clear and precise information; use of accessible language and in a timely manner; understanding the emotional state and of different forms of reaction of the parents; the formation of the bond; to listen; the reception and the humanization. To deploy these elements, the participants stressed, in fact, the possibilities involved in the communication and understanding of the information.

In this sense, the understanding of what is being announced depends on time to digest the news and that these are adapted to your intellectual capacity, to its social strata and culture,<sup>32</sup> which provides them with all the information to which they are entitled and which need to be considered and respected.

Meet their ideas, to communicate a story difficult, professionals should develop capacity to know his own feelings and thus must make contact with the unique experiences of the other in order to understand its limits and powers and assess how far he needs and can know.<sup>33</sup> Thus, the professionals participating in the investigation revealed that, when communicating difficult news the singularities and the realities they receive should be valued and respected, because they interfere in how these news are received and assimilated:

*“Of course comes the social part where each person is entered, the culture, the religion and various things that influence.” (P 17)*

*“She arrived, I don’t know who it was, I know he was a professional, ask questions and I answered where I live, if it was my first baby, born so because of that, and I just answered. Every day I arrived in ICU, they just said she (the daughter) was very premature and it was very serious because she was 27 weeks. I just said this.” (M 3)*

These fragments show that the difficult news media have a dimension which is existential and needs to be considered. Under this scope the professional should pay attention to the sufferings of the people, their emotions and their beliefs. Therefore, this dimension is of importance, not only for humanitarian reasons, but because it has important role in the therapeutic process.<sup>34</sup>

Points out that there are no two exactly the same experiences in dealing with the illness, and especially in the way professionals and mothers experience. There are two parts to this process: the disease (common to all) and the existential aspect (experiences, feelings, beliefs and emotions)<sup>34</sup> which are very different and need to be considered in the course of professional care. The authors<sup>34</sup> summarize these dimensions in stating that health professionals, particularly the doctor, interprets the disease while physical pathology (disease name, causal inferences, clinical, diagnostic and treatment assumption). The person (who experience the disease) plays in terms of experience (what it’s like to have this disease? Is this examination necessary? Is it necessary to do this procedure?). So are different perspectives to the same reality that lead to heterogeneous and diverse attitudes and reactions when considered the actors involved: on the one hand the professionals and the other are the mothers. In that respect, the provision of information is important, but the team must combine them the context of the situation and the implications for the mother and family,<sup>35</sup> that is, when communicating sharing is both the content and the meaning of information, because both are important to the decision making, a condition that states that the information should not be one-dimensional or one-way,<sup>35</sup> hence the complexity of the process involves communication difficult news.

Another issue to consider is gender differences. Mothers and fathers may differ in their perceptions, because their needs are different. It seems that mothers feel the need to participate in the process of illness and therapeutic child and have more control over the care while their parents feel secure with the team’s care. However, it is not possible in this investigation make such inferences, because parents did not participate in the research. However, the families are more effective as partners to the decision-making process, when they are engaged in an open and honest communication

with health professionals and when care is supported in the cultural beliefs, traditions and family structure.<sup>20</sup>

This process of respect and value each other in the process of communication of difficult news, although recognized by the interviewees, is a reality that often represents changes in the posture of some professionals, because “the prioritization of communication requires a professional change of focus and attitude, doing to listen, understand, comprehend, identify needs, and then plan the actions.”<sup>36:144</sup> in this perspective, skills for listening, questioning and exploring feelings are necessary elements for the promotion of emotional comfort positively influencing the psychological adjustment and the experience of the process of loss and uncertainty inherent in the illness.<sup>37</sup>

To listen sensitive is of extreme importance, because it enables you to meet and understand the essence of human care.<sup>5</sup> Thus, the investigation revealed that in their experiences realize the importance of listening with the parents, paying attention to their questions and concerns. Alia that the understanding that such a posture is essential to assist the families in overcoming possible conflicts arising from hospitalization:

*“Not only speak, but encourage the mother to ask what comes to mind and expose their questions.” (P 17)*

*“When we see that the family is available, which has a higher level of knowledge. We have to prepare for how we will speak. I worry, because depending on the mother I can use more technical terms that she will understand. That father that has a lower level of knowledge, I have to adapt my speech, knowing how I’m going to talk to him. We have to announce the news with a lot of calmness, tranquility.” (P 18)*

In the communication process is fundamental to active listening which supposes a professional able to listen. Sometimes, the short time due to the assistive pressure influence on insufficient communication making the Professional does not take time to listen, to respond to questions and understand the sufferings of the mothers. This condition brings implications for skills training for communication among the management of the speech, emotional expression and stimulate the exchange of information.<sup>38</sup> Another way, understanding the difficult news is not an easy process by the context of their content and the speeches of those interviewed showed how relevant factor in this process, the use of clear and precise information:

*“We need to facilitate this understanding, not too aggressive, but in a way that they (parents) understand that it is serious, that can have a more severe consequence. Needs to be said in a way that parents can understand the*



*situation of gravity. If we try to explain thoroughly, it may be easier, and somehow they will suffer less.” (P 11)*

*“I try to be clear, explain everything very detailed so that they can understand why we got to there.” (P 14)*

The difficult news must be communicated in a timely manner, gradually, clear and open, adapted at will, personality, understanding and need to know, manifested by the patient and family and their ability to participate actively in the decisions.<sup>39</sup> The timely condition means that the information meet the expectations of the participants (mothers and professionals) in order to search for sensible solutions and we both agree to establish dialog, i.e. Dialogic process efficient.<sup>40</sup> accordingly, the appropriate choice of words, since they can assume different connotations when they are being heard and that will remain in the memories of these families.<sup>41</sup>

Likewise, the process of communication suggests the professionals are open to needs of the mother and family, their concerns, fears and difficulties. This condition will result in benefit to the involved, in particular the mother, as these tend to enhance collaboration and support attitudes of professionals, not only the instrumental type, but also the spiritual, emotional, and informational support.

The use of a clear and understandable language in communicating difficult news were aspects recognized by mothers as essential in this process, and the lines show a recovery in the understanding of the information and that made a difference when the professionals, especially doctors, gave clear information concerning the preparation before examination and procedures and explained the results of the same. The mothers said that communication was easier when doctors use plain language:

*“When you go ask for a doctor or nurse and is explained right brings an encouragement in people. Many did this to me.” (M 8)*

*“She (doctor) I explained everything and everything was very clear. I talked to my husband about all she had said in this service and we decided and entered into an agreement to allow the surgery. If she hadn’t talked that way with me, explaining everything, it wouldn’t have made my son’s surgery until today. I would not have authorized. It was the only time I feel safe. And every time I call this doctor to clarify doubts me. I have confidence in her because I had the opportunity to talk with her.” (9 M)*

The understanding and assimilation of difficult news demand reflections on the importance of the assistance provided by the teams of the family health, because their actions are key to a more efficient and humanized attention in

news reporting process difficult, after all, the clear and simple dialogs avoid stressful situations. On that understanding, it should be noted that for mothers, receiving attention is a sign of the care professionals, they understand what they are feeling and needing at the time. Thus, respondents revealed that understanding, as it demonstrated an understanding of the guidelines and explanations when received by the mothers at the precise moment, their uncertainties and anxieties are minimized:

*“Some people are looking for the best way of intensive care to talk to me, spare me, speak all explained, without trying to mess with my emotional, because I’m very sensitive on this issue.” (M 6)*

*“We are looking for the words [...] get nicely tactfully to speak with a familiar and accessible language so that darkest me not to cause that impact and at the same time try to make it clear what’s going on.” (P 17)*

The approach of professionals with their mothers, encouraging them to adapt to unusual situations, from the information in a clear and objective about the situation of the newborn, was punctuated in the aspect lines of respondents, as it revealed the valuation humanized care. Allied to this aspect, the communication through empathetic attitude was highlighted as a factor that allows the emergence of a trust relationship between the one who receives the news and the one who transmits:

*“[...] arrive with affection and say what happened to the baby, he’s going to have to go through a treatment and that I should wait a day after another.” (9 M)*

*“Have professionals in the ICU who dedicate themselves because they enjoy what they do and know how to say things that are easier to understand. There are many doctors and nursing technicians arriving, with the way you talk, carefully choosing the words. Some try to clear up the problems, which just reassuring and giving us the confidence that we can rely on the team.” (10 M)*

The way the difficult news is presented can affect the understanding of those involved (and family) about her, its adjustment to and satisfaction with the professional. Therefore, competence, honesty, attention, and time to allow questions and clear language, are conditions for the communication of news difficult.<sup>42</sup> The humanization in the communication process of difficult news, molds from the emotional expression, empathetic and caring anyway when there is the establishment of empathic communication links are and make necessary interventions.<sup>43</sup> The empathetic attitude and positive emotions are factors that give health care



having effect on the good working relationship-familiar.<sup>19</sup> Such revelations require reflection on the relationship of professionals and family members in the communication process, because the words ratified the settings of these authors to defend that when family members have better communication and relationship with humanized the professionals have the opportunity to better understand the disease and its dynamics.

In the midst of such considerations is the need to host the unforeseeable, the different and the singular, in which practitioners seek to adopt practices considering the physical aspects, subjective and assuming an ethical social respect each other, approach to the unknown and the recognition of limits.<sup>33</sup> The reception represents receiving, caring and integrating the family members that the emotional experiences that occur during this period so they can be minimized.<sup>13</sup>

As well as the establishment of links between professionals and families, at the moment of diagnosis and prognosis graves reveal themselves as essential, the dialog promotes the communication of the health team and contributes to the establishment of effective interaction with the family.<sup>44,45</sup>

## CONCLUSION

The context of the NICU, considered aggressive and invasive, reflected by high intensity and complexity of events and situations. Has its own characteristics as the daily coexistence of professionals through the process of illness of infants, with the risk situations and the suffering and the pain of mothers and families. With an emphasis on technical and scientific knowledge and technology to meet the needs that demand changes and biological and physical disorders are permeated by tensions that require rapid intervention on the part of the team. However, this technical-scientific support may be compromised by the absence of the value the human person in his dignity and may be less hostile if health professionals are able to humanize practices, qualifying relationships, interactions and communicative processes. The fact is that technology and science can easily monopolize the attention of professionals and communication with the family can easily get lost in the list of priorities. Keep that way as one of the challenges in the environment of NICU care relations.

One of the implications for the practice of difficult news reporting process has proved that it is possible to communicate more effectively with their mothers and family, listening to them, requesting them contributions and suggestions, giving *feedback* and honest and maintaining adequate levels of security and reconsideration of the roles that mothers and professionals in care with the child.

Communicating quality appears as a professional social commitment. Therefore, it is important as a strategy for effective communication, validate through speech the other if there really was proper understanding and assertive content. The guidance, advice, answers to questions,

maternal attitudes of encouragement, support for mothers and the willingness to talk, were expressed as facilitators to conduct the communication of difficult news. Allied to these issues, to integrate culture in daily practices of the NICU was one of the important aspects for change in the way the team is positioned against the mothers.

The participants brought some implications for the communication of difficult news in neonatal intensive care unit which stands out: interventions that promote confidence; Recognizing behavior patterns revealed in mother-infant relations; opt for family-centered care; maintain, support and encourage participation in maternal care the child where appropriate; help promote and strengthen the family support network; increase the likelihood of behavior patterns for the development of bond/attachment and sensitive care to the environment and the special needs of mothers.

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Received on: 24/10/2014

Reviews required: No

Approved on: 17/09/2015

Published on: 08/01/2017

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