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ORIGINAL ARTICLE

THE UNVEILING OF CARE TO THE NEWBORN WITH CONGENITAL ANOMALY: PERCEPTIONS OF NEONATOLOGIST NURSES

O DESVELAR DO CUIDADO AO RECÉM-NASCIDO COM ANOMALIA CONGÊNITA: PERCEPÇÕES DE ENFERMEIROS NEONATOLOGISTAS

EL REVELACIÓN DE CUIDADO DEL RECIÉN NACIDO CON ANOMALÍA CONGÉNITA: PERCEPCIONES DE ENFERMERAS NEONATÓLOGOS

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ABSTRACT

Objective: to understand the perceptions of nurses in the care of a newborn with congenital anomaly. **Method:** qualitative study, carried out by means of interviews with 12 nurses from a Neonatal Intensive Care Unit of Rio de Janeiro/RJ/Brazil. The interviews were recorded, transcribed and then analyzed through content Analysis on the topic type, preceded by approval of the research project Committee of Ethics in Research, Protocol no. 2787/2010. **Results:** the analysis resulted in three analytical categories: 1. **Distinct Perceptions about the newborn with congenital anomaly;** 2. **Perceptions regarding the care to a newborn with congenital anomaly;** 3. **Perceptions centered in the family of a newborn with congenital anomaly.** **Conclusion:** taking care of a newborn with congenital anomalies can cause different reactions in nursing professionals, because each individual perceived them according to their social construction, judgments and values. **Descriptors:** Congenital Anomaly; Newborn; Neonatal Nursing.

RESUMO

Objetivo: compreender as percepções dos enfermeiros ao cuidar de um recém-nascido com anomalia congênita. **Método:** estudo de abordagem qualitativa, realizado por meio de entrevista, com doze enfermeiros de uma Unidade de Terapia Intensiva Neonatal do Rio de Janeiro/RJ/Brasil. As entrevistas foram gravadas, transcritas e posteriormente analisadas por meio de Análise de conteúdo do tipo temática, antecedida pela aprovação do projeto de pesquisa Comitê de Ética em Pesquisa, Protocolo nº 2787/2010. **Resultados:** a análise resultou em três categorias analíticas: 1. **Percepções distintas acerca do recém-nascido com anomalia congênita;** 2. **Percepções relativas ao cuidado a um recém-nascido com anomalia congênita;** 3. **Percepções pautadas na família do recém-nascido com anomalia congênita.** **Conclusão:** cuidar de um recém-nascido com anomalia congênita pôde ocasionar diferentes reações nos profissionais de enfermagem, pois cada indivíduo percebeu de acordo com sua construção social, juízos e valores. **Descritores:** Anomalia Congênita; Recém-Nascido; Enfermagem Neonatal.

RESUMEN

Objetivo: conocer las percepciones de las enfermeras en el cuidado de un recién nacido con anomalías congénitas. **Método:** estudio de enfoque cualitativo, realizado a través de entrevistas con doce enfermeros en una Unidad de Cuidados Intensivos Neonatal del Rio de Janeiro/RJ/Brasil. Las entrevistas fueron grabadas, transcritas y posteriormente analizadas mediante análisis de contenido temático, precedida por la aprobación de un proyecto de investigación en el Comité de Ética de la Investigación, el Protocolo N ° 2787/2010. **Resultados:** El análisis resultó en tres categorías: 1. **Percepciones distintas acerca los recién nacidos con anomalías congénitas,** 2 **Las percepciones con respecto cuidado a un recién nacido con anomalías congénitas;** 3. **Percepciones guiados por la familia del recién nacido con anomalías congénitas.** **Conclusión:** el cuidado de un recién nacido con anomalías congénitas puede causar diferentes reacciones en los profesionales de enfermería, ya que cada individuo en función de su construcción social percibido, juicios y valores. **Descriptores:** Anomalia Congénita, Recién Nacido, Enfermería Neonatal.

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INTRODUCTION

The congenital anomalies are morphological defects that are present at birth and occur due to multiple errors in the morphogenesis, being defined in malformations, ruptures, deformations, sequence and syndrome.¹ In Brazil, the congenital anomalies are in second place among the causes of infant mortality and third in mortality of children under five years old, being responsible for 10.5% of these.² Such indicators confirm that the anomalies constitute an important and current health concern, because they are emerging in substitution to other diseases and need of effective and quality actions, circumvention. Particularly with regard to primary level, health actions, having as a goal, trying to reduce the morbidity and mortality.

Faced with the position occupied by congenital anomaly, regarding the number of existing cases, it is believed that there is a wide repercussion for the health professionals, mainly in the tertiary level, in particular those that are closest this clientele, the nurses. Being that the care, object of nursing work, it is necessary to exercise it with quality and directed towards the individual's demands, in order to meet their needs, regardless of their disease, with emphasis for the humanization of care.

The humanization represents a set of initiatives aimed at the production of health care capable of reconciling the best available technology, promoting acceptance, ethical respect and cultural to the patient, of work spaces conducive to good technical exercise and satisfaction of health professionals and users.³ Each member of the team should have sensitivity to deal with the hospitalization of newborns, placing the baby as the subject of care, seeking to individualize the care.⁴

In Neonatal Intensive Care Units an aggressive environment can be seen for neonates depends on specialized care by professionals, all the technological apparatus aims at maintaining vital signs and clinical recovery. In this regard, the support to mothers and their families is very important because everything is considered new to them, which requires increased surveillance on the part of health professionals⁵.

Perception deals the apprehension of an objective situation based on sensations, accompanied by representations and often of judgments. Unlike the sensations, it is not a photograph of the objects in the world exclusively determined by objective qualities of the stimulus. In the perception, to the

stimulus were added elements of memory, reasoning, judgment and affection, therefore, engaging the objective qualities of the senses and other subjective elements specific to each individual.⁶

Considering the above the guiding question of this study is << How does the nurse perform the care that they give to a NB with a congenital anomaly? >> to give an answer to this question the following objective was drafted:

To understand the perceptions of nurses in the care of a newborn with a congenital anomaly.

METHOD

This study is a part of a Nursing Coursework conclusion << The unveiling of care to newborns with a congenital anomaly: perceptions and coping strategies of neonatologist nurses >>, developed in a Neonatal Intensive Care Unit of a University Hospital, located in the municipality of Rio de Janeiro.

This is a qualitative study, with 12 nurses who participated in the direct care of newborns with congenital anomalies; they are professionals who dedicate most of their working hours caring for newborns in more serious states. The data construction period occurred in the month of December 2010 to February 2011.

Before starting the interview an informal dialog was instituted with the subject in order to establish a rapport with the purpose, also, to learn if they had already participated in the care of a newborn with a congenital anomaly, this being the criterion for inclusion in the survey. Those who answered affirmatively, we invited to participate in the study, after the verbal consent, the subjects were informed about what was contained in the Term of Informed Consent, which describes the principles that involve the ethics of research (autonomy, beneficence, non-maleficence and justice), and the use that would be made of the data.

It was opted to perform an interview with a semi structured script, which was recorded on an MP3 device, having as the guiding question << How does the nurse perform the care that they give to a NB with a congenital anomaly? >>

The treatment of the information obtained during the interview is anchored on the content analysis of Bardin⁷, in thematic modality, with pre-analysis, exploration and codification of the material, and interpretation of the results. Concurrent

effectiveness of to the interviews performed to their transcription. Upon completion of the interviews, exhaustive readings were conducted which led to their encoding, unfolding, grouping and synthesis of testimonies, resulting in three analytical categories: 1st. Distinct Perceptions about the newborn with congenital anomaly. 2nd. Perceptions regarding the care to a newborn with congenital anomaly; 3rd. Perceptions centered in the family of a newborn with a congenital anomaly.

This research meets the recommendations of Resolution 196/96 of the National Research Council, and submitted to and approved by the Ethics in Research (Protocol No. 2787/2010) of the institution where the research was conducted.⁸

RESULTS AND DISCUSSION

♦ 1st Category- Distinct Perceptions about the newborn with congenital anomaly

This category depicts the perceptions that the participants face with a newborn with congenital anomaly, as well as reactions, difficulties and feelings that permeate this experience.

By perception that the person identifies how the others are and assign meanings to their actions and form impressions about them where the behavior of individuals is based on the interpretation that make the reality, and not the reality itself.⁹ Consistent with the experience of interviewees it is note in the parts of the speeches, what each one valued as being their perception of reality:

[...] so, it was difficult, I was afraid, insecure, the RN was purple, and cyanotic [...]. I was very insecure and afraid as I performed the care [...]. (E01)

I am afraid even to move or hurt the child causing them pain, not knowing how to handle them feel pain [...]. (E02)

Through the reading of the statements of interviewees above it was possible reveal that if faced with a child with congenital anomaly it is a difficult situation for the nurses, bringing out different perceptions, such as: Insecurity; fear of performing the care; fear of moving them; injuring them; not knowing how to handle them; fear of the child feeling pain. In addition, for the interviewees to see a malformed newborn it is something that frightens them, causing an impact, impressing and is ugly to see.

[...] you are frightened with that [...]. (E10)
We are impacted; this affects us [...]. [...] because it impresses everyone, they are anomalies, as well, it is an ugly thing to

see, is not something beautiful, therefore we are impressed [...]. (E11)

However, regardless of these perceptions, generally, they remain, although there are feelings, reactions, the subjects were aware of their role as professionals in the area of nursing, and they do not fail to fulfill their responsibilities.

[...] we look, at what frightens us; we swallow it and have to care for them. (E11)

Act in taking care of the different is an arduous task and brings broad repercussions, professional and personal, because accepting the different is complex. In the maternity ward, for example, despite being a hospital field the expectations are; life, joy and fulfillment of dreams. The birth of a child with malformations does not correspond to these expectations and this leads to thoughts about personal issues that, many times, generate conflicts.¹⁰ However, it should be noted in some excerpts of the speeches that the nurses mentioned that the congenital anomaly is not reason of estrangement, because some statements show the difference is these newborns, if compared to other newborns.

For me a newborn with congenital anomaly is a child as any other [...]. (E03)

I do not see any difference, I really do not see [...]. (E4)

Other statements show different perceptions in relation to newborns with external anomalies, portraying the external anomalies as something that frightens and others relate that these anomalies do not cause shock and some type of impact.

It is for me as well, it was very difficult the first contact, I went there to see a child with gastroschisis, then looked, it was frightening. (E02)

And there [in the hospital where they work], as we see a lot the intestinal level, which is the gastroschisis and omphalocele it is ... when I was working there for the first time, I was shocked, and said, this exists, oh my [...]. (E6)

Thus, it became clear that each individual has, therefore, a peculiar way to envision the same situation and can give it a different meaning. In all, there is a perception that the affective component contributes to the image portrayed. Some impressions can be captured more intensely than others, depending on the attention (affective interest), depending on the conceived attitude, state of mind and emotional state of the perceiver. Therefore, the perceptions are subjective by existing in our consciousness and objective by their content that stimulates the sensation.⁶

A study done in the year 2008 shows that watching the birth of a malformed child puts the nurse ahead to an unusual and undesired situation, requiring emotional control, so that they don't interfere with the results of the care, which is conducted by a multidisciplinary team. The nurses feel powerless facing the situation of the birth of a malformed child, because it is a condition apart from that of routine care, having to act in accordance with the status and conditions of the newborn, requiring a different way of conducting care¹¹.

Although, the external anomaly, causing in some professionals estrangements, in others, it may be considered as natural and not causing negative reaction.

[...] these questions of external anomalies, which for many people shocks, to me it does not, so do not give this, this reaction [...], then these situations so that the principle, the aesthetic, the appearances, which shocked more in some situations, for me it doesn't cause any major reaction [...]. (E11)

This behavior can be caused because each one perceives according to their experiences and life history. What one should not do is judges the perception that the other has given to situation because each one recognizes their own limits and potentialities.

♦ 2nd Category- Perceptions regarding the care to a newborn with congenital anomaly

The nurses, in their statements, demonstrated differences in their reports in relation to the care they provide to newborn infants with congenital anomaly. Because part of them believed that the care must be different and special due to the anomaly that the RN presents and another assumes that the care is equal and as to any other child, that there is a differential in this care and that the anomaly does not interfere in any way. Faced with the fact it is highlighted that no babies survive without care, whether the biological mother or a mother substitute. Moreover, in the Neonatal Intensive Care Unit, nursing acts as the mother substitute in an attempt to meet, whenever possible, the needs of the newborn.¹²

The care, being the object of nursing work, is very clear and evident in the practice, particularly in relation to the care to the NB with congenital anomaly, which proved so unique and divergent in this study.

The care with the child ends up that is equal, them having a congenital abnormality, a congenital anomaly or not. (E10)

In this context, certain deponents are faced with the duality in relation to the vision of care to newborns with congenital anomaly, because in their reports they stated that they pray the care is equal and pray that the care is different.

[...] The care that you pay for it will be different because of the care that they inspire the the care of a low weight NB, a full term NB [...]. (E03)

The nurses also evidenced the care to newborns as a duty/obligation.

[...] this is my duty; my duty is to take care for this newborn [...]. (E07)

Unfortunately the people work in a hospital that have a lot bad training and ends up that this happens in our daily life, not like a natural thing, something that does not call our attention, but happens and we have means in which to get over it and give the care [...].” (E10)

In short, the reports show that the nurses who consider the careful differential, refers to the disease, but not the appearance in itself the newborn with congenital anomaly. Moreover, that even with the anomaly there is no interference with this caution, because the same if they feel in duty and obligation to take care of these newborns, with this there is a differentiated treatment due to its appearance, but in relation to the disease and the peculiarity that it presents.

In view of the foregoing, it considers the culture of social groups, it is understood that the Nursing, in addition to composing a holding group of a certain culture, interacts with the other, individual or social, through their work object that is the care/caring. Thus, it is understood that the care is not restricted to a mere act or a task for intervention of determined organic dysfunction, but the actions promoting a universal balance of the human being.¹²

♦ 3rd Category- Perceptions centered in the family of a newborn with a congenital anomaly

The majority of nurses pointed out that the differential in relation to the care that they provide to the newborn infants with congenital anomaly is the family, in particular the mother.

[...] the one who has to differential, which I see too, it is in relation to the family; the care that you have to be with the family, with a mother who is always present there. (E04)

One of the excerpts from the speeches emphasized that one of the variations in the care of the family is the concern in relation to their mother's emotional state, because

according to the nurse a rejection of the family and the mother can happen not interacting directly with the child complicates the situation further. Anchored in the family-centered care, it is incumbent upon the nursing team provide a free demonstration of maternal feelings, soothing the painful sensations, strengthen the bond between mother and child, respecting the family characteristics and the way which this confrontation occurs.¹³

[...] changes even the issue of emotions, you see the question of the mother, can often be a rejection of the family or the mother does not interact directly, there it gets complicated [...]. (E09)

The unexpected presence of a congenital anomaly can quantitatively and qualitatively impair the establishment of the mother-child relationship. The magnitude of an early and appropriate intervention along with the parents is justified by a substantial impact that the malformed child exercises, may result in the formation of a precarious bonding, and even maternal deprivation, which can disturb the emotional stability of the individual in a prolonged and constant manner. Therefore, the nurse occupies an important position, because, with their attitudes, it can influence in a positive or negative way the relationship between the malformed child and the family. The commitment should be to act as facilitator of the formation for this bond, because this relationship will have a profound impact on the future development of the child and on the unfolding of their personality.¹⁰

Another highlighted speech states that nurses recognizes that the family care of the NB with a congenital anomaly changes, because the mother is not aware about the anomaly and that causes fright and estrangement. The important thing is to pay attention to these characteristics and show to this mother that she may be with the child and in the majority of cases, do things with them as if they did not have an anomaly, but instead any other disease. Therefore, a support for the family is necessary, since the resources employed by the family, according to the interviewees, are different.

Changes, changes, regarding to the family changes yes, [...], the mother did not know that, do not know what it is, because at the first moment it causes fright, it causes an estrangement, then well, you have to is on these things, paying attention to these things and how you will be able to show that mother [...]. You are very much connected to this support for the family,

because they do not have the same resources. (E04)

It has been noticed, in recent years, a movement of health professionals in order to cover the family care, accompanying them and helping them to establish affective contact next the child. Thus, the professionals have begun to encourage parents to talk to the baby, to touch them, to bring significant objects from home, including performing some care such as feeding and hygiene¹⁴

At least my differential is always with the family, that the look of the family for that child and my look at that mother, it is different; it is a look cozier, try putting this child, if possible, in her lap [...]. My differential, I think that it is with the family, is trying to bring this family more of this child. (E10)

Most congenital anomalies is characterized as chronic diseases that accompany the individual throughout their life. Thus, the team and the health system as a whole must be prepared. The Professionals need to foster a systematic care for these patients and their families, supporting them and encouraging them in coping with everyday problems, and the interdisciplinary team can be configured in a link of strengthening and social support.¹⁵

The interviews reveal that when the NB with congenital anomalies is in the NICU, they are faced not only with the care of the NB, but must deal also with the parents and family. In this situation, the nurses, may be faced with some difficulties.

(...) but I think that at the time that we see the mother, the mother looks for the child and the mother is falling apart by having malformed baby and that sometimes the bad training is, therefore, very striking, very external, this time is the most difficult moment, not caring in nursing, but this moment is for dealing with this family and with this mother. (E10)

[...] for the professional, the greatest difficulty is adaptation, the reaction and the entire context and behavior with regard to the family that is what it is, that is what most interferes, that is the most difficult to care for." (E11)

The nursing staff, upon watching the birth of the malformed child, perceives their experience as stressful, awkward and uncomfortable, permeated by difficulties, being the main one of them showing the child to the father, to the family and, in particular, the mother.¹⁰ When we deal with a child with congenital anomaly, the difficulty to integrate the family is still greater on the part of the team, because the team itself does not know how to deal with this situation.¹⁴

When approaching the family who experiences the care of the child with congenital anomaly, has the opportunity to reflect on the professional practice in nursing. With this, it recognizes the lack of these professionals being present, above all, in the everyday family, supporting them in dealing with problems, especially in periods of adaptation, serving aid, providing adequate information, counseling paths to follow facilitating access to necessary services and, especially, developing professional attitude and sincere staff listening and receiving in their time of crisis.¹¹

Another data shown in the findings is related to the fact that the nurses in the care of a child with congenital anomaly just putting themselves in the place of the mother and raising awareness before some situations, such as for example, to pass through the same situation, also producing a child with an anomaly or in relation to the behavior of the mother.

You are there taking care of this baby and end up putting even as a woman, as a mother, it puts in place, often the mother's... (E07)

The mother is in the question put myself sometimes that suffering of that mother there, you just end up putting yourself there and sensitizing in some situations regarding the mother's behavior. (E11)

There are three possible reasons that lead people to feel discomfort in interactions with the deficient: the first refers to the way the different changes the stability and predictability of social interactions. The malformed does not match the social perspectives, and we do not know how to deal with it, we do not know what to expect of it. The second reason is that we have experienced feelings of ambivalence in relation to them; this is because, at the same time that we do not like the different, we are people educated to protect the weakest. Before the malformed, generally, we feel penalized, but concomitantly, this feeling generates others not so noble, as the selfishness and, in this way, we were pleased by the fact that the problem may not be with us. The third reason is because the presence of deficient in serves to permanent indication of threat that hangs over us, threatens this unpredictable and irreversible.¹⁶

In this reality, acting professionally when caring for a child with congenital anomaly may be a triggering factor for different meanings for the nursing workers, particularly mothers, women, in phase of the constitution family or those already structured personally,

because the reality of the work environment can do with what you think a mixed reactions and feelings that may interfere in their personal and professional lives.

CONCLUSION

The study revealed the perception of nurses, as well as the dualities, difficulties and limitations present in this experience. Taking care of a newborn with congenital anomalies can cause different reactions in nursing professionals, because each individual perceived them according to their social construction, judgments and values. In this study, the nurses reported, among other perceptions that permeate this caution: Insecurity; fear of performing the care, to handle, to hurt, to not know how to handle, the child feel pain; it is not a pleasant thing; frightens; shocked; it is difficult; impresses; is shocking; it is ugly to see; but as the perception is of particular individual some interviewees reported that they do not suffer from impact to take care of a newborn with congenital anomaly.

The care of a newborn with congenital anomaly is a challenge for the entire nursing team, because they are the professionals responsible for patient care and the ongoing process of caring. Another relevant factor encompasses the relationship of nursing professionals with the family of the NB, which provides even more the involvement and enables an affective bond between professional/family/newborn. Therefore, this study pointed out some challenges for the health professionals and, in particular, to the nurse, ahead when taking care of the newborn with malformation and his family, who treat under the aegis of the implications for nursing practice.

To ensure that the quality of care in hospital scenarios, particularly in the Neonatal Intensive Care Unit, to establish before anything, it is necessary to rethink professional training. In this regard, it is known that even today, the syllabuses focus on very biological and pathological aspects of human beings, but we did not have reflect and discuss more about the content inherent interpersonal relations and communication abilities professional/family/patient.

In This way, the results corroborate with the relevance of an emotional support to be provided to professionals who work in the care of newborns with congenital anomaly. In a practical way, what we suggest is the participation of the psychology department and the construction of a therapeutic group for which the professionals expressing

themselves and feel more empowered and prepared to cope with the peculiarities and adversities of their work scenario. We believe in the importance of nurses and other health professionals understand the need to take care of themselves to be a balance in caring for the other, avoiding emotional and physical exhaustion, and providing an effective care.

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