Fetal malformation incompatible with life: the conduct of neonatologists

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Abstract

To evaluate the behavior of neonatologists in cases of malformation incompatible with life, from intrauterine diagnosis to delivery, and the use of palliative or curative-restorative care at birth, with or without the prior awareness of physicians or parents on fetal infeasibility, we carried out a qualitative research in a Brazilian maternity hospital. From semi-structured interviews and content analysis, we observed that most professionals do not adopt cardiopulmonary resuscitation techniques when the situation is already clear to the parents; that the criteria for palliative care are linked to the confirmation of the syndrome diagnosis, through information to the family; that the parents' awareness about the disease can influence decision making; and that the establishment of palliative care, if only the physician knows about the fetal infeasibility, in most cases includes due information to parents.

Keywords: Neonatology. Infant, newborn. Congenital abnormalities. Palliative care.

Resumo

Malformação fetal incompatível com a vida: conduta de neonatologistas

Para avaliar a conduta de neonatologistas em casos de malformação incompatível com a vida, do diagnóstico intrauterino ao parto, e a instituição de cuidados paliativos e/ou curativo/restaurativos ao nascimento, com ou sem o conhecimento prévio dos médicos e/ou pais sobre a inviabilidade fetal, realizou-se pesquisa qualitativa em maternidade brasileira. A partir de entrevista semiestruturada e análise de conteúdo, observou-se que a maioria dos profissionais não adota manobras de ressuscitação cardiopulmonar quando a situação já está esclarecida aos pais; que o critério para cuidados paliativos está vinculado ao diagnóstico de certeza da síndrome, mediante a informação da família; que o conhecimento dos pais sobre a doença pode influenciar a tomada de decisão; e que o estabelecimento de cuidados paliativos, no caso de apenas o médico saber da inviabilidade fetal, inclui na maioria dos casos a devida informação aos pais.

Palavras-chave: Neonatologia. Recém-nascido. Anormalidades congênitas. Cuidados paliativos.

Resumen

Malformación fetal incompatible con la vida: conducta de neonatólogos

Con el fin de evaluar la conducta de los neonatólogos en casos de malformaciones incompatibles con la vida, desde el diagnóstico intrauterino hasta el parto, y la institución de cuidados paliativos y/o curativos/restaurativos al nacimiento, con o sin el conocimiento previo de los médicos y/o padres sobre la inviabilidad fetal, se llevó a cabo esta investigación cualitativa en una maternidad brasileña. A partir de una entrevista semiestructurada y análisis de contenido, se observó que la mayoría de los profesionales no adoptan maniobras de reanimación cardiopulmonar cuando la situación ya es clara para los padres; que el criterio de cuidados paliativos está vinculado al diagnóstico de certeza del síndrome, a través de la información familiar; que el conocimiento de los padres sobre la enfermedad puede influir en la toma de decisiones; y que el establecimiento de cuidados paliativos, en el caso de que solo el médico sepa sobre la inviabilidad fetal, incluye en la mayoría de los casos la debida información a los padres.

Palabras clave: Neonatología. Recién nacido. Anomalías congénitas. Cuidados paliativos.

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Professional ethical dilemmas, especially in cases of newborns with malformations or syndromes incompatible with life are frequent in neonatology, as they involve people who cannot answer for themselves. In these circumstances, medical conducts should be based on bioethics, understood as a set of moral principles that govern individual rights and duties related to health, as established and accepted at a given time by a given society[1]. Given that the Greek origin of the word "ethics" can be related to customs, as well as the Latin origin of the word "moral," bioethics has been pointed out as a "science of morals" or "philosophy of morals"[2].

According to Souza and Goldim, ethics is the most important component of life, giving it meaning in its formation process, and it is concretized daily in caring for others – something *as simple in its general formulation as complex in terms of its day-to-day performance*[3]. Medical ethics follows the ancient tradition of reflecting on moral dilemmas in healthcare, and the Hippocratic oath has been perpetuating severe ethical determinations for the profession since ancient Greece[4].

Scientific and technological advances bring new and several ethical questions associated with the increasing complexity of medical practice and sociocultural changes. As a result, since the 1980s, ethics has been increasingly invoked, valued, and questioned, and the activities and responsibilities related to this set of moral principles have expanded progressively and continuously, creating new challenges every day[5].

Healthcare for women and children is strongly affected by emotions, beliefs, values, and interests that are often conflicting, and may, in some cases, produce complex moral dilemmas[6]. For example, in fetal therapy, issues focused on the adequacy of risky procedures for pregnant women may have an uncertain benefit for the fetus[7]. In certain cases, we should consider whether the fetal intervention is appropriate. But these ethical issues overlap each other, as they imply a specific fetal diagnosis that will influence the future quality of life of the child, and also raise problems from the specific moral *status* of the pregnant woman, who decides on her medical care, directly reflecting on the possibility of the fetus survival[7].

The governments of the world have been proposing different treatment strategies for newborns with malformation or extreme prematurity. Rhoden[8] distinguishes three different approaches. The first, statistical prognosis, particularly used in Sweden, gives the fetus with an unfavorable prognosis the right not to be born. The second, in the United States, proposes to wait until the diagnosis is confirmed, beginning in all cases intensive treatment with regular reassessment of the individual prognosis, and admitting the possibility of suspending therapy in the case of expected death or irreversible coma. Finally, in the last approach, the individual prognosis is evaluated to start intensive care in almost all newborns, often reevaluating the situation to stop the treatment when the prognosis is bad; this strategy includes interventions in extremely preterm infants to broaden the diagnosis and define the conduct[9]. Rhoden's[8] findings changed the perspective on this conduct in different countries, although there is still no consensus.

The lack of formal training in ethics or bioethics of most neonatologists can affect the way they deal with these situations[10]. Those who do not have this training feel free to discuss prognosis and treatment options, but not to address emotional and social issues, and still have difficulty in suggesting palliative care and addressing the family's spiritual and religious needs. All of these aspects are essential for decision making in cases of malformation incompatible with life[11].

Intense feelings of helplessness and fear are triggered by the diagnosis of malformation. Early detection during pregnancy allows parents to prepare themselves to face even the grieving process. On the other hand, the family's suffering can be aggravated when the anomaly is identified only after birth. Parents do not expect the child to be born ill, which is why the professional must be prepared to support them[12].

In this scenario, we propose to evaluate the conduct of neonatologists in a teaching hospital in Southern Brazil, which is also a reference center in high-risk pregnancies, in cases of malformation incompatible with life, from diagnosis to outcomes, including delivery and the institution of palliative or curative-restorative care at birth, whether or not physicians or parents have prior awareness of fetal infeasibility.

Method

This research has a qualitative epistemological basis whose design started from the perception of its legitimacy in the health sciences. The qualitative method was applied due to the need to know a set of interpretative practices and obtain descriptive data about people and interactive processes through direct contact between the researcher and the topic studied [13,14].

The sample was intentional and represented by 11 neonatologists who provide care to newborns in a public and humanized maternity hospital in Southern Brazil. Of the 13 professionals invited to participate, two were excluded for being temporarily removed from their duties. The participants were approached by the researcher during her working hours in the respective sectors. They were directly invited and presented to the research project and to the informed consent form.

We carried out the study in the neonatal intensive care unit (Neonatal ICU) of the University Hospital Professor Polydoro Ernani de São Thiago (Florianópolis, Santa Catarina), which is linked to the Federal University of Santa Catarina. The maternity hospital attends an average of 180 births per month and has nine neonatal ICU beds.

The data were collected in 2018 with a semi-structured interview adapted from Guedert [15], composed of a fictitious clinical case attended by a physician on duty: cesarean delivery due to maternal preeclampsia; the newborn is premature and has several malformations already diagnosed in prenatal care, such as intrauterine growth restriction, interventricular communication, omphalocele, microcephaly, and cleft lip. These observations led to a karyotype exam that diagnosed Edwards syndrome. Considering this, four questions were elaborated (three of which were open, and one closed), questioning the conduct of the professional, the institution of palliative or curative-restorative treatment, and the degree of information of the parents or the physician regarding malformation incompatible with life, influencing or not the decision making process.

The quantitative variables were analyzed using descriptive statistics, and qualitative variables with the Iramuteq software and content analysis. With the software, we carried out descending hierarchical classification, similitude analyses (both tree and dendrogram), and word cloud. In the content analysis, the material was previously explored through searches, and the units of analysis were selected, categorized and subcategorized until data saturation.

Results and discussion

Conduct

The results obtained with the software and content analysis were similar. In the former, the synthesis of the responses was "I do not resuscitate children when I have already discussed with their parents about the diagnosis of incompatibility with life." In the second analysis, most of the answers (63.3%) was categorized as "I do not resuscitate if the diagnosis was discussed with the parents," and a small portion (27.3%), in the category "I do not reanimate," regardless of the parents' degree of information.

Among the interviewees, only one made explicit that he would perform cardioplumobary resuscitation if the family had no prior awareness of the child's diagnosis: *"If I have time to talk to the parents before birth, I discuss with them about not having an intervention; without this conversation with the parents, I proceed to resuscitate the patient, I do all the procedures"* (E6).

The conduct of neonatologists after an indisputable diagnosis of a malformation incompatible with life, such as the fictitious clinical case here presented, is in line with a recent publication by the Brazilian Society of Pediatrics [16] about palliative care. However, we highlight that the discussion with the parents must consider cultural, religious, moral and legal family aspects. Ethical and bioethical precepts help physicians to decide what is the best for a specific patient, thus avoiding measures that can cause unnecessary suffering without improving quality or lifetime [17].

Decision making: palliative or curative-restorative treatment

For all participants, the fact that the patient had already been diagnosed with Edwards syndrome was decisive for making a decision. Four of them (36.4%) emphasized the importance of considering the family's awareness. The result was similar with both techniques of data analysis, as shown by the following statement:

"The first criterion is the syndrome, which is incompatible with life; we already have the karyotype, so the diagnosis is clear. If you don't have the karyotype, if it is just a suspicion, then you may have to investigate better the case during the evolution of the condition. But here we have a situation incompatible with life, and the parents are aware of that" (E2).

With technological advances, including those in the field of fetal medicine, it becomes possible to diagnose congenital malformations with great precision even during intrauterine life. When the prognosis is incompatible with life, parents should

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be informed. The medical team can indicate the most appropriate way of delivery for the pregnant and offer newborns basic support, with palliative care, but without invasive procedures[17]. In these cases, the Committee on Fetus and Newborn from the American Academy of Pediatrics states that life support is inappropriate, as well as when the treatment is deemed harmful or futile[18].

In this sense, the parents' opinion, the dialogue with the medical team, and possible external medical consultancy must be taken into account. Moreover, the terms of the decision and the reasons for the conduct must be documented in a medical record[19]. Although professionals are morally obliged to respect the autonomy of the parents and allow them to exercise their role, if they insist on interventions considered technically inadequate, the team should clarify them about possible damages and suffering inflicted on the newborn, giving them emotional support and maintaining a respectful dialogue, regardless of disagreements[20].

As emphasized by the participants, the family's awareness is an important aspect, which does not mean disregarding non-maleficence and comfort measures for dignified conditions for the newborn at the end of life[21].

Decision making versus parental awareness

After analyzing the dendogram of hierarchical classification, similitude analysis, and word cloud, we found that the respondents consider that the parents' awareness about the diagnosis influences decision making. This result was also corroborated by the content analysis, which indicated this trend for most participants (90.9%). With this analysis technique, we observed that neonatologists valued the family's level of understanding, knowledge, and desire.

In all cases of fetal anomaly diagnosis during the intrauterine period, the pregnant should be informed about therapeutic possibilities and probable hospitalization period, as well as prognosis. Consequently, the health team must define the accuracy of the diagnostic method and its implications for pregnancy, childbirth, and neonatal period[17].

Families benefit from the opportunity to prepare and plan the arrival of the newborn with a diagnosis of a pathology incompatible with life, which includes supporting the mother during delivery and involving the father in the situation. In such cases, a birth plan can be developed in advance, indicating care for the newborn after birth. Communication during this process is essential, especially when deciding not to resuscitate, intubate, or medicate intravenously, or use any other invasive measure[22]. It is important to remember that the main role of medicine is to maintain life, but not to prolong it when there is no prospect of improvement or well-being[22].

The decision on any procedure is always up to the pregnant and the father. The physician does not necessarily need to agree with it, but must understand it without recriminations, and when the medical staff and parents disagree, the case must be referred to the Ethics and Bioethics Council. In specific situations, such as in cases in which the prolongation of the newborn's life would generate only suffering for everyone involved, the most prudent approach, that is, shortening suffering, can be taken[23].

Thus, the parents' awareness is very important in the management of the case, but it should not be the main determinant in the choice of treatment, which does not prevent the medical team from providing clarifications, resolving doubts, and sharing information about the measures that will be utilized after birth.

When only the physician is aware of fetal infeasibility due to malformation

In this hypothesis, the data analysis with the Iramuteq software revealed that the respondents choose to resuscitate the baby and use palliative care and measures until it is possible to talk to the parents, so that they understand the diagnosis of a syndrome incompatible with life. In the content analysis, 63.6% of the occurrences determined palliative care for the baby accompanied by information provided to the parents, while 18.4% categorized the immediate institution of palliative care, 9% showed difficulty in deciding in these circumstances, and 9% indicated that the decision is of the medical team, with the family's awareness. According to respondent E1:

"I think that to offer palliative care to a patient we need good communication; the family must be absolutely aware of everything, and comfortable in relation to palliative care. If the family had not the opportunity to know the details of the case, it is not at the time of delivery that this has to be done. Then, we would probably assist the baby in a slightly more aggressive way, a little more invasive, until, as early as possible, the contact with the parents is established. After we explained everything, removed all doubts, then we would offer palliative care."

The lack of awareness by family members regarding the infeasibility of the newborn results in a conflicting and delicate situation, but the predominance of palliative care was evident, as well as the need to inform the parents. In the answers the participants stressed the relevance of the family's awareness in the whole process and that their opinion can influence the decision regardless of whether the conduct is a medical team's prerogative or not. This is evidenced in the statement of E10:

"I think the family should always be together, talking, so that they are aligned with the team. I think they have to be aware of the conduct that will be taken by the medical team. But it is not a family decision, so I think it may even be a very bad thing for them in the future. The medical team evaluates, the medical team makes the decision, and the family is aware. I think this is important."

If the neonatologist is alone and unprepared to decide whether to resuscitate the newborn or assume more restrictive conduct, providing only basic care to avoid suffering or minimize it, it is preferable to take a more active attitude, performing all steps of resuscitation, including procedures such as intubation, mechanical lung ventilation, cardiac massage, and medication, when necessary. Subsequently, with clinical data and complementary tests in hand, and after talking with the parents, it is possible to choose to offer palliative care [24].

Although the literature widely supports that after the diagnosis of a malformation incompatible with life, all treatments should be suspended, this decision can be emotionally complex. The health team must be very convinced that this is the best for the patient even before talking to the family. Only after the entire team, the family, and the ethics committee agree, advanced life support can be suspended and palliative care can be offered [25].

Therefore, nothing is preventing intensive care or even resuscitation maneuvers from being carried out until a conversation with the parents, explaining the pathology, its main risks, the absence of available treatments, and the prolongation of suffering [26]. After all parties are clarified, palliative care can be instituted, and eventually, treatments considered as "futile" suspended – which, despite reaching therapeutic goals, do not cure the clinical condition – or "useless", when they do not reach these goals and do not benefit the patient [26].

Final considerations

Given the fictitious clinical case of genetic diagnosis of malformation incompatible with life, we observed that most neonatologists would choose not to institute cardiopulmonary resuscitation maneuvers when the situation was already clarified to the parents. The criteria for starting palliative care are linked to the diagnosis of the syndrome and to the family's awareness, which can influence medical decision-making. Finally, palliative care must be used only when the physician knows about the fetal infeasibility and gives all available information to the parents.

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Participation of authors

Mariane de Mello Rossini conceived and designed the research, developed the qualitative analysis and descriptive statistics, analyzed and interpreted the data, and wrote the manuscript. Ana Maria Nunes de Faria Stamm made a critical review of the manuscript for intellectual content and supervised it as a responsible researcher.

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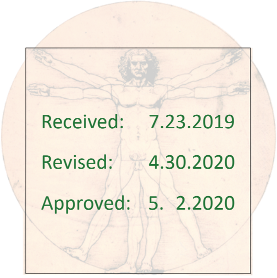

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