



## DILEMMAS AND DIFFICULTIES OF INTENSIVE PHYSICIANS INVOLVING DISTANASIA IN CHILDREN

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### ABSTRACT

**Introduction:** Dysthanasia is the practice by which the life of an incurable patient is prolonged through artificial and disproportionate means. This concept is a field of discussion of the value of human life and death. The work in the ICU places the doctor in confrontation with choices and decision-making involving technical, ethical and moral aspects deeply imbricated to the technological incorporation in the health area.

**Objective:** The objective of this study was to know how physicians at neonatal and pediatric ICUs mean distanasis.

**Method:** Exploratory / descriptive study, qualitative approach. Six physicians and five residents belonging to the neonatal and pediatric ICUs of a teaching hospital, high complexity, a reference for municipalities in the central region of the state of Rio Grande do Sul, participated in the study. We used a semi-structured interview, the information was transcribed and analyzed from content analysis.

**Results:** Dilemmas and difficulties were observed that encourage physicians to conduct themselves as distanásicas: to define in practice the terminality, the differences of conduct between professionals, the obstinate requests of the families to invest in the patient, as well as the fear of ethical and legal repercussions.

**Conclusion:** It was observed that the dilemmas, anxieties and anxieties that involve these themes make their action, in the assistance, something that deserves a special attention, because in the academic formation what is expected and what is often learned is preserving life, providing healing and never waiting for death.

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### INTRODUCTION

The determination of the irreversibility of life is a condition of extreme difficulty, since it implies establishing with relative certainty that a patient is irrecoverable.

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This determination is particularly difficult in children, studies indicate that many children die in pediatric ICUs as a result of a decision to limit or suspend lifesaving measures or to not resuscitate and not prolong further suffering and pain.(1, 2) Since the mortality in a pediatric intensive care unit ranges from 5 to 15%, the great majority of children admitted have a high expectation of cure. Therefore, the independent sense of the gravity of the picture, is to take measures to save the life.

The determination of terminality in these situations takes some time to establish with certainty that the child is in an unrecoverable situation. (3) The increasing use of technology in health causes misrepresentations in the processes of dying, putting medicine in check, within the limits of its ability to "heal." (4) As a result of the denial or avoidance of death postures, it is difficult for the health professional not only to deal with death, but also to care for the dying patient (5). One of the causes of suffering of the health professional is the feeling of impotence / omnipotence in the face of the possibilities and limitations of medicine and the consciousness of finitude to which the professionals are subjected, when they deal with a reality where the disease and the imminence of death are so real (6,7). From the wide range of possibilities that technological advancement offers today, health professionals, especially ICUs, are experiencing intense dilemmas about "how much to invest without aggression?" Or "how long to prolong life?" (8, 9). As noted in this research, these are the larger, more intense, and deeper issues that influence the significance of dysthanasia, regarding the dilemmas experienced by intensive care professionals regarding the terminally ill child admitted to the ICU. Thus, the work in the ICU places the medical professional in confrontation with choices and decision-making involving technical, ethical and moral aspects deeply intertwined with the technological incorporation in the health area. Depending on his decision, he may either interrupt the care or make resuscitation efforts (10). In this context, this study presents results from a research that had as main objective to know how physicians of the neonatal and pediatric ICUs mean distanasia.

## MATERIALS AND METHODS

To reach the proposed objective, a descriptive and exploratory qualitative research was chosen. Eleven physicians responsible for the routine of the Neonatal and Pediatric ICUs were interviewed, and the total number of physicians at the unit, including effective physicians and residents, were 20. Of the 11 interviewees, 6 were effective physicians and 5 were residents. The age range ranged from 25 to 45 years; the formation time ranged from 2 to 23 years; all interviewees were women. The research site was a high complexity teaching hospital, located in the central region of the state of Rio Grande do Sul, Brazil. Where the service is a reference in health for 45 municipalities in the region. Data collection took place between February and June 2013. The project was registered in the Department of Education, Research and Extension (DEPE) and submitted to the evaluation of the Research Ethics Committee (CEP) of UFSM, and resulted in a Master's thesis. For the data collection, semi-structured interviews were used, the interviews were recorded and later transcribed for analysis purposes, the data went through a Content Analysis<sup>11</sup>. After the "floating reading" of the collected material, emergent topics were categorized according to the criteria of relevance and repetition<sup>12</sup>. All the ethical recommendations proposed in Resolution 510/16 of the National Health Council 13 were maintained, thus, the interviewees had voluntary participation, without institutional or psychological coercion, instructed with consent. To maintain the anonymity of the participants, the names were changed by the code MED and RES, followed systematically by the number of the interview, thus presented as: MED 1, MED 2, MED 3 and RES 1, RES 2, RES 3, successively. The research was approved by the Research Ethics Committee of the institution where the research was carried out, under the

number of the Presentation Certificate for Ethical Appreciation (CAAE): 11664712.6.0000.5346.

## RESULTS AND DISCUSSION

### A (in) definition terminal patient

The definition of a terminally ill patient is not a simple one to establish, especially when professionals are in their practices. The definition for the terminal patient is a condition of irreversibility presenting a high probability of dying within a relatively short period of time ranging from three to six months (15). Faced with these notes, it is essential to point out how medical professionals define and determine the terminal patient in their work environment, when this is discussed in an abstract way, unrelated to a specific case:

*[...] in the pathologies that are known to have no prognosis and are going to die, for example, those genetic alterations, serious malformation ... which does not have to do so, so in those cases we try to maintain quality until death. (MED 6)*

In fact, there is some consensus regarding the definition of terminal patient; still, it is noticed that the conceptions of the doctors resemble those found in the bibliographies. However, it is not considered an easy task to define a terminally ill patient, even terminal expression is complex and risky, because a patient with a fatal and serious disease can, at certain moments, return to their activities, thanks to the dizzying advance of the therapies today employed. It can be said that it refers to a concept, inaccurate, even because life itself is already terminal in itself (16).

In this context, there are some statements that demonstrate the uncertainties regarding the determination of the terminal patient. The diagnosis of terminality disappears when the discussion is brought to a more concrete plane, appearing, at that moment, the subjective questions:

*[...] I think the only time that stops to give a more adequate support is the time that is proven brain death, because the others, if everything. (MED 4)*

*So, many people do not even know it's terminal right, many of us do not even know it's terminal. And in the terminal patient does not change much, right, because in the end everyone wants everything done. (RES 1)*

In fact, what we can understand here is that many doctors do not seek to reflect on terminality. It is perceived that they are concerned with knowing how to examine, diagnose, treat and cure. There may be no time within the ICU for a reflection on terminal patient care, and this may be linked to the functioning of this sector, which has a technological arsenal to save lives that require a hurry in diagnosis and treatment, which may often lead to automatic decisions, in order to save the patient.

*[...] several babies who were preterm infants ... these patients were even terminal patients in the neo that you have a multiple organ dysfunction so ...if you stop to think you can not imagine a life out of an ICU, out of a mechanical ventilation, or drugs ... that enter a vicious circle of infections that sometimes you can not even define very well .... (RES 5)*

A determining factor is based on the uncertainties of the medical team how to act before the patient. In the case of children, the justification for maintaining the investment is often supported by statistical data, which shows a low mortality in the PICU and, consequently, a high expectation of cure (17). Still, according to the professionals' report, the children surprise the professionals themselves who often consider the irreversible case.

*[...] the risk of dying is great, but we try everything in these cases, because they are the most surprising right, children have a potential for great improvement, look, they are always surprising, several times already found that there was no return and they ended up having an improvement that no one expects. (MED 2)*

*[...] a patient who fell from the third floor, no one gave more hope to the case, because his skull really was broken, he spent a long time in a coma [...] until one day he woke up and improved, improving, improving until he walked out of the ICU listening, without any sequel know, so I say wow, but really also happen miracles, because of course, we also gave all technical support, but what I was commenting, often you giving the technical support right, people die, but there are other cases like this that he woke up one day, without anyone giving more expectation [...]. (MED 1)*

Thus, believing that the child has no possibility of cure is a condition of extreme difficulty for the physician, since it implies to establish with security that it is irrecoverable. Doctors consider that because they are children, the definition of irreversibility is a difficult and time-consuming process, since they believe that children have a greater chance of recovery when compared to adult patients<sup>18</sup>.

Thus, in situations where the physician continues to believe that the child can be cured or in situations where he does not have the time to feel safe as to the ineffectiveness of the curative treatment, he chooses to maintain the therapy for the cure that has been offered. Moreover, the lack of protocols that allow the diagnosis of the patient's lack of definition may be the basis for the low frequency of use of the "terminal patient" diagnosis:

*[...] we should have organized the protocols well, because it is very difficult as I said to know the moment of this terminality. I think they do not have specific scales for children, only some that have been modified but I think this would be very important to do, well cool. (MED 1)*

In this sense, the constructions of meanings for dysthanasia are also interconnected to the question of deciding when the patient is terminal, especially for the various doubts that arise in this context, since there is no standardization of conduct to be practiced towards the terminal patient, especially in ICUs. Thus, in Brazil, as in Latin America in general, there are no assistance protocols that indicate standards for the care of incurable or terminal patients<sup>19</sup>.

The resistance in diagnosing a patient as a terminal also concerns the fact that it is a definitive diagnosis, which, however, may not be confirmed by the evolution of the case. Thus, it is believed that, after considering a patient as terminal, the health professional is in a paradoxical situation, because if there is improvement, this will indicate the professional's

failure to perform the prognosis. In fact, the diagnosis of a terminal patient without a back is distressing for the health professional<sup>20</sup>.

Consequently, the most complex factor, when it comes to terminality of life, is precisely to determine it, is to identify a patient as terminal or to consider a certain interval as being consistent with the end of life, either as a consequence of an exacerbated chronic disease or for any other reason. In this sense, what you have in your hands is merely a "guess" until the moment death comes (21).

### Divergences of conduct

Health professionals fight against death with all the technological arsenal at their disposal. There is, however, a moment when the struggle comes to an end and one must stop investing, otherwise one would not only be imposing unnecessary expenses but disrespecting human dignity. However, the problem is addressed in the question of establishing the limits of conduct, since there are divergences and uncertainties of professionals (22). From the data found, the doctors stated that they are troubled by the lack of unanimity in decisions that involve the end of life. In this context, in addition to the actions that may become isolated, it is added that medical decisions at different times do not follow a unanimous behavior, which often contributes to the indecisions facing situations involving the end of life. One of the doctors said that on one occasion, on her shift, she tried hard not to put a baby on the respirator, however, on a later shift the other employee did.

*[...] statistically he has no chance of surviving and he was ... should not have been put on the respirator and what? [...] This is the moment that we are, the people, I say, the majority, is in anguish because you know that if you put on the respirator, you will prolong ... I still said to the nursing, the people you have to do everything to not go to the respirator, because if it is, it will not go out any more ... it will not go out ... it will rent the respirator, we will be doing things for it, right (MED 6)*

From the speech presented, it is perceived that the decisions seem to be permeated by a lack of objective criteria in relation to the situations that present themselves, that is, they seem to be performed according to the conceptions of each professional. From another angle, in the ICU, the work is performed through shifts. In particular, the physician exercises his / her activities as a caller, a fact that the distance of the patient decreases the possibility of establishing affective ties with the patient, his / her relatives and also with the team (23). And this characteristic of the ICU can generate conflicts, especially of practical order. In addition, one concern that can intervene decisively in the care of the terminally ill patient in the ICU is the high turnover of physicians on call and the great discontinuity of the ducts. Thus, this factor can directly influence the establishment or continuation of futile measures or preference for limiting life support and palliative care (24). Consequently, among the differentiated characteristics of the physicians who deal with the terminal patient in the ICU and, above all, the absence of a routine doctor to follow the evolution of the cases on a daily basis, there is no consensus of conduct, as doctors themselves emphasize:

*[...] I get there on duty, it's hard to know what it's like to do with this baby. But of course many times is determined, right,*

*people go on duty ... and it's registered there "should not be invested", right. So when this is defined we do, but, the problem is this, it is almost never defined right. So the colleague goes there and intubates I'll get there and say "oh, why did you intubate?" Only you do not take off, right, how are you going to take it. He can not, but then I come and fight, "but because he intubated, he should not have intubated." (MED 6)*

Regarding these divergences of conduct, what has been observed in the ICU is that there is a lack of communication among doctors, especially in relation to occasional on-callers. Communication can become an enigma when there are technical language problems, whether verbal or non-verbal. If it is already complex to understand the scientific "confusion" of diagnosis and therapy in relation to therapeutic obstinacy, what about the "mess" among health professionals because they simply do not communicate? These problems, as mentioned by the author, are mainly related to the clarity of the messages, because if they are ambiguous, they can cause confusion and insecurity for the team (25).

Some professionals reported feeling ill, distressed, with the lack of definition of conduct. Sometimes this was even determined, but at the "H" time, the doctor would come back. Therefore, the absence of a synchrony of conducts in the face of the situations imposed in the ICU is perceived with discomfort on the part of the professionals (24). The following statements (or would they be?) Express such ideas of the author mentioned above:

*[...] there's the baby that's very serious that ... so, it's bad, it's there with a respiratory distress that is known to intubate just to prolong, but then a confident think you can hold, not to intubate, but here comes the other and intubates, here comes the third and criticizes who intubated or why they have not intubated before. So, this is not a criticism of anyone, nothing special, but, because it has not defined, right. If it had defined that the child is bad, it is so, it is asking for tube but it does not have prognosis you will not intubate, we would respect. (MED 6)*

In this perspective, medical professionals are often distressed by the difficulty of interacting with other professionals in their area, which makes it impossible to provide adequate patient care. There is great difficulty deciding, especially deciding solitarily. This fact imposes on the professional a "crossroads", in which he does not feel able to intervene with a view to avoiding dysthanasia. However, he is also aware that delaying the process of dying, in addition to adding to the agony of the patient, is an unethical procedure that also causes him certain suffering (26).

The stubborn requests of the family

*"They always ask: save my son, do everything, do what you can and can not". (RES 1)*

The talk above has made room for discussion about the influence of the family's dogged demands during discussions for decision-making. "If everything is done" is the phrase most used by parents facing the possibility of losing a child, most often, through the words of doctors it is perceived that the request is to invest the maximum. Thus, it is noted that the family exerts a strong influence in relation to the medical

conducts towards the terminal patient. Charges from the family are very common, which asks the doctor to prolong the life of the patient, for different reasons. Among them, it can be inferred that the lack of psychological preparation to deal with death may be one of them, since few people have this preparation, according to the participants of the research. As a consequence, feeling pity, anguish or impotence, among other feelings, the professionals rethink their evaluations about the requests of the relatives who obstinately request that some procedure, although futile, be performed in the patient, with the intention, in vain, of cure or control their disease (27).

*[...] This relationship is never easy, because there is that family that ... how do I say ... that wants at all costs, even you saying that you have nothing to do ... I do not know no ... we end up even arguing with them ... ah ... but most of the time they want everything to be done, to get reassured, to have no limits right .... (MED 2)*

*[...] But most of the time we talk, explain to parents that they have nothing to do, they understand, but at the very moment they want to invest and what is worth is their opinion. We can not not invest if they want. It does not change the prognosis, it does not change. He will die in a few hours, he will, almost always this is how it happens, but he will. It may take a little longer, but it will. (RES 1)*

As is clearly stated in the above dialogue, the reason for the therapeutic obstinacy, of offering useless measures to the terminally ill patient, is due to family pressure. The family, with its feelings, ambivalences and consequent obstinate requests directed to the team, exerts a strong influence on the representations regarding the medical conducts towards the terminal patient. Thus, in front of these positions, which start from the professional experience of the doctors, what exists is that they see in the familiar someone who interferes and makes the doctor responsible for the results with his patient. Corroborating, the authors 20 express that "the relatives and patients prefer to believe that the doctor has the dominion over life and death, that is, they wish to believe that the professional is infallible in their fight against the disease. On the basis of this assumption, many of these impasses are in keeping with this attitude, mainly because of the difficulties of exposing the patient's real condition to his family members, and also because of the insecurity and fear of ethical and legal repercussions in these situations.

*[...] no one wants the baby to stop on his or her shift, no matter how good it is, it's hard for you to do nothing, it seems like we're going to the other, and hoping that it will not fall on my watch right. (MED 3)*

The fear of feeling guilty or of the family blaming him for death leads the doctor to keep the treatment curative and to intensify efforts to keep the child alive, or as in the following report, he ends up masking the attitude of not reanimate, because it can be attributed to the omission of distress.

*[...] comes the nurse and says: this child made a stop, there his father there, then I'll tell you what happens sometimes, what we call the theater right, you pretend to reanimate, only this is not right, we know that you have to assume and do not do this theater, you do not have maybe a culture ... because maybe you do not have a support you do not have that commission that decided not to reanimate and really not to reanimate,*

*because this family can agree with you and tomorrow she will come to justice saying that they did nothing and that they killed the child right, and you can not say no because this family is very emotionally involved right ....(MED 2)*

The feeling of a lack of legal support creates a conflict between whether or not to incur therapeutic futility. What was evidenced through the speeches is a feeling of extreme discomfort in relation to an unclear theme, regarding ethics and Brazilian legislation. This lack of clarity between closing the diagnosis of terminality, between investing or not investing in the patient, between hearing the opinion of the family and the team, etc., leads the professional to two essential fears: either to undergo ethical or judicial process, or to commit an act that is not the best for the patient, when it comes to the therapy to be offered to it.

*[...] todo mundo tem um pouco de medo do que legalmente pode acontecer né. E as vezes a gente sabe que ah, conversou com o pai e ele me disse aquilo, mas depois ele muda de opinião e daí sobra pra mim sabe. (RES 5)*

*[...] pelo medo de alguma complicação principalmente com a família né, a gente termina fazendo coisas além do lógico sabe, colocando em ventilação mecânica, drogas pra manter a pressão e os batimentos cardíacos, mas mais por essa questão legal, por não ter um código bem estabelecido[...]. (MED 1)*

Even today, some doctors express their fears and fantasies regarding the legitimacy and legal support to limit the offer of curative therapy in patients in the final phase of irreversible and progressive disease. For, they understand that the limitation of therapeutic effort in this group of patients could constitute infraction to some articles of the code of medical ethics (CFM, 1988) and maintained in the current code (CFM, 2010), such as: Article 1 (It is forbidden to the doctor to cause injury to the patient by action or omission, characterized as malpractice, recklessness or negligence), and to Article 32 (The physician is prohibited from using all available diagnostic and treatment means available scientifically and within their reach in favor of the patient ) (29, 30). This creates insecurity, which is explained as follows:

*[...] we went to take a course with a UTI doctor from the United States, uh ... it's a pediatric intensivist [...] he says that in fact we can not have that culture of doing it doing , doing it, but it's because there they have another culture, right there they assume they will not do anything and do nothing ... the doctor stays on the side of the patient, the family and you do not do the theater, stopped, do not reanimate , it is not even here, and there they say that there it is well defined, they are well supported by the legislation. It's not even here, and there's only comfort, but here we do not have to, we can not help doing nothing, it's very difficult to decide that [...]. (MED 2)*

In order to resolve these and other doubts, the current Brazilian code of medical ethics (31) has made explicit in several articles and paragraphs the need and ethical duty of the physician to provide palliative care for patients suffering from incurable and terminal illness. The authors (32) emphasize that "the promotion of care to patients with terminal illness, beyond curative therapeutic possibilities, depends primarily on the acceptance of human finiteness and the recognition of the medical inability to cure always." For this, the professional must consider that the commitment to save lives and exhaust

the technological possibilities is less valuable than providing the relief of suffering for the child and the family.

*[...] we ended up arguing with the Bioethics Committee here, and I think it's very important, right, it was very helpful, right, right, if it was to invest in that baby. Because they were babies that we were very much in doubt so, if it was us ... because the parents wanted to invest a lot and there was not much, practically nothing like that to do, just palliative care right. (MED 3)*

*But I've learned here ... that we have to think a lot about life at any cost ... we're doing crazy things to save a child who has no prognosis at all .... (MED 6)*

The current concept of palliative care is "an approach to the quality of life of both patients and their families facing problems associated with life-threatening diseases. The action seeks to prevent and alleviate suffering through a precise and careful evaluation and the treatment of pain and other symptoms, whether of a physical, psychosocial or spiritual nature " (33).

However, it has been shown that, even in developed countries, palliative care is requested late and for a small portion of applicants. In a study involving children under one year who died in the PICU and NICU, palliative care was requested and provided around 2.5 days before death and for less than 15% of the deaths<sup>34</sup>. With such difficulty in mind, the American Academy of Pediatrics in 2000 warned and emphasized that "general pediatricians and their pediatric subspecialties must be familiar and trained to be able to provide palliative care to children in their care" (35).

## Conclusion

From this study, it was observed that the medical practice in Pediatric and Neonatal ICUs is surrounded by dilemmas when the subject that comes to the fore is dysthanasia. The dilemmas, anxieties and anxieties that surround these themes make their action, in the assistance, something that deserves a special attention, because in the academic formation what is expected and what is often learned is the conservation of life, the propitiate healing and never expect death. With regard to these dilemmas, among the meanings of doctors about dysthanasia in children are the differences of conduct between the colleagues themselves; because they often confront each other with their ideals, goals and subjectivities in the care of the terminally ill. As there is not yet a parameter to establish clearly the decisions of conduct in the terminality of life, the professional confrontations are inevitable. Moreover, health professionals themselves consider that decisions about dysthanasia are influenced by relatively subjective aspects. Regarding the divergences of conduct among the ICU team, it is important to note that there is a greater space for dialogue between routine and on-callers, since, without it, agreement becomes more difficult and prolonged, since the various perceptions about the whether or not the child's recovery needs to be considered, discussed and analyzed in order to reach a consensus on the cessation of therapeutic investment. Until a consensual decision is reached among the medical staff, the child continues to undergo the curative treatment initially proposed. Due to these dilemmas, the importance of the implantation of a palliative care unit is verified, with the purpose of operating end-of-life care. Also the creation of a committee of bioethics in the hospital in order to subsidize the

discussions about the terminality, what would give or would support the practices of limitation or proposition to the death worthy of the patient in the imminence of the same. It is recommended, therefore, that the preparation for working with terminal patients should start in the undergraduate courses themselves, since this is part of the skills that health professionals should have; and make it impossible to see the terminal patient as a defeat, a lost case to see him as a human being who can and does need to be helped at this stage of his life. An improvement in the way the health team handles the end of life would not only reduce stress but also improve performance in their work. In addition to instruments that provide them with ethical and technical subsidies, the need to create spaces that give support to the affective aspect of the professionals dealing with death and the terminal patient in their daily life is noted. In order to do so, it is suggested that moments be given to discuss the issues of death and dying, both in the academic and hospital settings, providing the elaboration of the fears and fantasies of the health team in the face of the unknown that this question involves.

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