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# Ethical Considerations in Neonatal Respiratory Care

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## Key Words

Bioethics · Newborn · Resuscitation · Mechanical ventilation · Palliative care

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## Abstract

Recent advances in neonatal care have greatly improved the chances for survival of very sick and/or very preterm neonates and have in fact changed the concept and the limits of viability. However, in some situations, when the infant's demise can only be postponed at the price of great suffering or when survival is associated with severe disabilities and an intolerable life for the patient and the parents, it may be unwise to employ the full armamentarium of modern neonatal intensive care. In those circumstances withholding or withdrawing mechanical ventilation and other life-saving, though invasive and painful, procedures might be a better option. This review examines the ethical principles underlying those difficult decisions, the most frequent circumstances where they should be considered, the role of parents and other parties in the decision-making process and the reported behavior of neonatologists in many American and European neonatal intensive care units.

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Dedicated to W.A. Silverman, with whom we, as many others, have a great debt of gratitude for his contribution to our scientific, professional and personal growth.

## Introduction

The first anecdotal reports of artificial ventilation of newborn infants date back to the early 1800s [1]. However, it was only in the early 1950s that intermittent positive pressure ventilation, thanks to the pioneer work of Donald and Lord [2], gained acceptance among neonatologists. Since then, there has been a progressive and substantial improvement in neonatal respiratory care technology, with the introduction of more and more sophisticated mechanical ventilators and esoteric techniques, such as the various modalities of synchronized positive pressure ventilation, high-frequency oscillatory ventilation and, on the pharmacological side, intratracheal administration of exogenous surfactant [3, 4].

These advances in respiratory care have certainly contributed substantially to the spectacular improvement of survival of sick neonates, particularly those who are preterm. Apart from its acute life-saving role, mechanical ventilation 'buys time' for the spontaneous maturation and recovery of the lungs and other organ-systems of the preterm infant, and allows the use of a whole spectrum of therapeutic interventions which are typical of modern neonatal intensive care. On the other hand, the power of mechanical ventilation is such that it can sustain life even in situations where recovery will never be possible, in the presence of severe cerebral damage or even brain death, thus prolonging suffering for the child and the family.

The evolution of neonatal intensive care has led to a number of important changes in the organization and delivery of maternal and child health care that are rele-

vant to the problems to be discussed in this paper. The availability of sophisticated and complex therapeutic tools, requiring highly specialized and experienced personnel, has promoted the regionalization of perinatal care and the creation of a limited number of large centers equipped with the necessary human and technological resources for the care of high-risk patients. The overall aspect of these neonatal intensive care units (NICUs), with their remarkable display of technology, busy people, strange sounds and blinking lights, may be intimidating to parents and, unless appropriate measures are taken, may increase anxiety and contribute to depersonalization of the parent-staff relationship. At the same time, the capabilities and needs of the neonate and the importance of early mother-infant interactions for the child's development and for the welfare of the whole family have started to be recognized. This has led to the opening of NICUs to parents, thereby transforming a traditionally private and inaccessible territory into a semi-public space, and further increasing the complexity of interpersonal communication in an emotionally charged environment. In particular, the presence and active participation of the parents in the NICU has contributed to their empowerment both as 'supervisors' of the staff and as inevitable contributors to the decision-making process concerning the care of their infants. At the same time, the uncritical dissemination of the successes of intensive care among the lay public has raised expectations of society and parents regarding the potential of neonatal medicine, sometimes unrealistically, leading to further problems with relations and even to legal disputes.

The existence of ethical issues regarding the care of neonates, particularly when disabled or dying, has long been recognized [5]. In contrast to expectations, technical progress has not allowed us to overcome these issues; rather it has moved the focus of ethical debate to smaller and even more frail babies.

In this paper we will briefly examine and discuss some of the most important ethical issues that can arise in neonatal respiratory care, including the applicability of the traditional ethical principles in NICUs, in which situations it may be appropriate to withhold or withdraw mechanical ventilation or other forms of heroic treatments, who should be the persons involved in such decisions and what are the current practices in many NICUs around the world.

## Ethical Principles and Decision-Making

Beauchamp and Childress [6] have identified four principles of clinical ethics as a guide to clinical decision-making. *Autonomy*, or the right to self-determination, prescribes that each person's values and wishes are respected. Neonates, however, are not autonomous persons. In neonatal medicine the principle of respect for autonomy applies to the parents who are, in general, the legitimate surrogate decision-makers for their children. However, parents are not the only persons involved in decision-making; the autonomy of other parties, such as physicians and nurses, also deserves consideration. *Beneficence* and *nonmaleficence* prescribe the duty to benefit and not to harm other people. It is debated whether not harming (the famous 'primum non nocere' attributed to Hippocrates) should or should not take priority over the duty of beneficence. According to Gillon [7], a prohibition to do harm would virtually render the practice of medicine impossible, as most diagnostic and therapeutic acts imply some type of harm. Thus, beneficence is what the physician should be most concerned with. In fact, beneficence and nonmaleficence should be seen as two sides of the same coin: the balance between them is the crucial issue, as we will see later. The last principle, *justice*, implies fairness of treatment and, from an economic perspective, fairness in the allocation of available resources: an objective which should be acquiring increasing prominence in the modern world, where globalization demands considerations of justice to be carried out at international rather than national level. Among definitions of fair treatment, the most famous is attributed to Aristotle: 'Equals should be treated equally, and unequals unequally in proportion to the relevant inequalities'. [8]. In medicine, justice requires treatment decisions to be free from considerations of race, ethnicity, or ability to pay.

The four principles approach represents a useful tool for systematic analysis of ethical cases, less so for making decisions. Principles tend to conflict with each other. Decisions considered by physicians as beneficial to their patients may violate the autonomy of parents, if they do not agree, or even be 'harmful' to other siblings. Principles in themselves are not hierarchical, and in case of conflict they must be balanced with each other. The process depends on the context and on the personal values of the various parties, and can therefore be considered to a certain extent arbitrary [9].

More recently, two criteria have emerged as a relatively better guide to decision-making: the so-called *best*

*interest* standard, and the *proportionality* criterion [6]. Best interest implies giving priority consideration to the welfare of the patient, and to what is best for him/her. While the best interest standard inevitably includes elements of 'quality-of-life' judgment, it has however the merit of focusing attention where it should belong, the patient himself. In its strictest interpretation, the interests of other parties (parents, siblings, society) do not count, and no patient should be left untreated to protect the interests of others. Some authors, however, point out that the interest of a baby, particularly if sick or impaired, is inextricably linked to that of the family [10] and at least in the most catastrophic situations the burden to parents and siblings should also be taken into account. To determine what the best interest is, the expected benefits of continued treatment must be weighted against the burdens. Only treatments that are 'proportionate' (a term which has come to replace the old definition of 'ordinary means'), and therefore capable of offering a net advantage to the patient, have to be considered obligatory.

In the context of neonatal respiratory assistance, there are two situations where issues of ethical decision-making may arise: deciding whether or not to start it and whether or not to withdraw it. The first type of decision often arises in the delivery room soon after birth; the second at any time during the hospital stay, and even later if mechanical ventilation is continued at home. Withholding and withdrawing mechanical ventilation carry with them somewhat different medical implications and psychological weight, and therefore they will be dealt with separately.

### **Decision-Making at Birth**

There are cases where prognosis is sufficiently well clarified antenatally that a decision on whether or not to resuscitate and start mechanical ventilation may confidently be made before birth. A good example is anencephaly, where a consensus exists that comfort care rather than intensive respiratory assistance should be provided. Other, less clear-cut examples may be fetal chromosome abnormalities which are incompatible with prolonged life, such as trisomy 13 and 18. In these cases, the issue of communication becomes of paramount importance. Communication with the parents involves the transmission of relevant information regarding diagnosis and prognosis in a clear and sympathetic way, listening to their concerns, answering their questions and explaining what type of care will be provided to their baby at birth

and afterwards. Communication, however, concerns also the health care team, so that all the necessary actions are well planned beforehand and no undesirable decisions are made by individual personnel due to lack of preliminary agreement, or clear definition of the selected strategy.

Rarely, however, is the prognosis so clear-cut. Most of the time some uncertainty exists regarding either the exact diagnosis or prognosis. In these cases, decision-making at birth becomes a critical step, as it has the potential to initiate a cascade of events that lead to admission to the intensive care unit, starting mechanical ventilation, fostering parents' bonding and raising their expectations about survival, starting invasive, expensive and generally painful procedures, long-term stay in hospital and, often, an imperfect outcome [11].

At the level of the individual patient, the most frequent case of prognostic uncertainty is represented by the birth of an infant at very low gestational age, a situation which has been brought about by advances in medical technology, and particularly the ability to use mechanical ventilation in smaller and smaller babies. In discussing the appropriateness of resuscitation for these infants, reference to the issue of 'viability' is often made. The concept, however, is cloudy, and its definition ambiguous and open to different interpretations.

Webster's dictionary gives two definitions of 'viable' as: 'capable of living', and 'capable of surviving outside the mother's womb without artificial support' [12]. From a neonatologist's perspective, the two definitions are obviously very different. In line with the first one, as early as 1984 Dunn and Stirrat [13] proposed the limit of 22 weeks' gestation and/or 500 g, recommended by WHO for reporting of perinatal statistics, arguing that 'although only a few infants born at 23 weeks' gestation (500–600 g) have as yet survived, their numbers are likely to increase with the advancing skills of neonatal intensive care'. Since then, the outcome of preterm babies has indeed improved, but Dunn and Stirrat were exceedingly optimistic in their assessment as survivors at 23 weeks' gestation are still quite few, and important concerns exist about their long-term health. As suggested by Rennie [14], it is better to link the concept of viability to survival free of major disability rather than survival alone.

In recent years some large, well-designed studies have provided data on survival and long-term outcome of very preterm infants. Wood et al. [15] in the UK reported an extremely poor survival before 23 weeks' gestation (1%), with a slightly better but still very poor prognosis if the baby had been admitted to an NICU (9%). Survival im-

proved with increasing gestational age: 11% at 23, 26% at 24 and 44% at 25 weeks. The overall disability rate among survivors at 30 months was 49%, and 23% met the criteria for severe disability. Very recently, data on the health outcomes for the UK cohort at 6 years of age have been published [16]. The rates of severe, moderate and mild disability were 22, 24 and 34% respectively. Compared with their classroom peers born at term, 41% of the extremely preterm children were affected by serious cognitive impairment. In the population-based French study Epipage [17], none of the 46 babies born alive at 22 and 23 weeks in 1997 survived to discharge, compared to 31% at 24, 50% at 25 and 56% at 26 weeks. In Belgium, the Epibel study [18] provided data from babies admitted to the 19 NICUs in the country in 1999–2000: survival was 5.5% at 23 weeks and 29% at 24 weeks. More recent data document an improved survival of 40% at 24 weeks [19].

Survival figures and long-term outcome are also influenced by the physicians' approach to resuscitation and subsequent care of these tiny infants. Many studies have documented the variability of neonatologists' attitudes, particularly in the gestational age interval where survival is possible but unlikely, and risk of future disability high. A study carried out in 2002 in six New England states explored the opinions of neonatologists towards resuscitation according to gestational age [20]. At 23 weeks, almost 90% of them considered treatment to be of uncertain benefit, and the same position was held by about half of respondents also at 24 weeks. Before 23 weeks, 82% felt that treatment was futile (defined as 'treatment that will not significantly extend life or postpone death'), while at 25 weeks a similar proportion (84%) viewed it as clearly beneficial. When respondents considered the benefits of treatment to be uncertain, 100% reported they would resuscitate at parental request, and 98% also if parents were unsure. Should parents, in the same situation, prefer to forego treatment, 76% of neonatologists would comply; about a quarter of them (24%), however, would initiate resuscitation despite parental opinion, and allow the baby's evolving clinical condition to dictate further decisions.

Variability in perinatal management appears even larger at international level. Confronted with the hypothetical case of a 560 gram baby born alive at 24 weeks, with a 1 min Apgar score of 1, most neonatologists participating in the EURONIC study (1996–1997) [21] would resuscitate and start intensive care. In Italy about half of them would do so even if intensive care would not be withdrawn once started. In UK, Sweden, France and

Germany the vast majority of physicians would resuscitate with the understanding that intensive care would later be withdrawn in the case of poor prognosis. In contrast, in the Netherlands most physicians (63%) would withhold resuscitation at birth in accordance with national professional guidelines discouraging active treatment before 25–26 weeks [22], while 37% would resuscitate and make subsequent decisions according to the infant's condition and response to treatment. More recently, the EURONIC project was replicated in Ireland, using the same questionnaire and methodology of the original study; in the event of the birth of this 24 weeks' gestation baby, all Irish physicians would resuscitate at birth; however, 82% would do so with the understanding that intensive care can later be withdrawn if poor prognosis is confirmed [Samaan C, pers. commun.].

Attitudes vary also according to the staff's professional background. In a study carried out in Australia in 1997–1998 [23] about 40% of neonatologists reported that they consider 23 or 24 weeks as the lowest gestational age for resuscitation, with a median value of 24 (range 22–25). In contrast, among nurses the median lowest gestational age was 25 weeks (range 23–28). Streiner et al. [24] confirmed that physicians tend to be more optimistic than nurses regarding the probability of survival and freedom from major disabilities, and would recommend life-saving interventions at earlier gestational ages. According to Ballard et al. [25] fear of litigation may increase the rate of resuscitation of infants born at the limits of viability.

Taken together, these findings suggest that resuscitation at birth is generally considered futile before 23 weeks and beneficial from 25 weeks onwards. In the 23–24 weeks' interval, neither futility nor beneficence can be safely invoked. At these gestational ages, most neonatologists in Western Europe, with the notable exception of Italy, might accept to withhold resuscitation at parents' request. However, when parents agree with resuscitation or are uncertain, treatment is generally provided. In any case, an approach to resuscitation based solely on gestational age can be viewed only as a rough indication. This should be modified on a case-by-case basis according to postnatal assessment including the correct gestational age, the presence of associated congenital defects or perinatal asphyxia, the vigor of the baby and his/her general health.

## Decision-Making in the NICU

A solid consensus exists in the literature that withholding (not starting) intensive care is morally equivalent to withdrawing (stopping) it [6, 7, 26]; if anything, the latter approach should be viewed as more justifiable as it allows a better assessment of diagnosis and prognosis, and of the prospective benefits and burdens, so that decision-making is based on more secure grounds. Both not starting and stopping may be examples of allowing patients to die. However, uncertainty about outcomes may be reduced by a trial of therapy, and physicians and surrogate decision-makers may feel more in control if a decision to treat can be reversed should treatment prove ineffective.

Nevertheless, there is little doubt that, for health personnel and also for parents, treatment withdrawal carries with it a different psychological and emotional weight and, in some countries, an even higher risk of legal liability. One might perceive the act of withdrawing, rather than the underlying disease, as being the cause of death. In the EURONIC study [27] the majority of neonatologists (from 45% in Italy to over 80% in the Netherlands, UK and Sweden) reported having participated at least once during their professional life in decisions to withhold intensive care. In contrast, clear-cut decisions of withdrawing mechanical ventilation were reported with very different frequencies in the various countries: again over 80% in the UK, the Netherlands and Sweden, but only 61% in Germany, 36% in Spain, 28% in Italy. The reason for withdrawing intensive care is also important. In all countries the majority of doctors reported having participated in nontreatment decisions in cases of fatal or terminal illness, while the proportion of such decisions on quality of life grounds (poor neurological prognosis) was lower particularly in Italy, Spain and Germany [27]. Apart from country, other factors appear to influence physicians' decisions with regards to ethical issues in the NICU, pointing to the role of Unit policies and even physicians as individuals, including gender, age and length of professional experience, religiousness and personal attitude towards the sanctity versus quality of life [27, 28].

If it is considered legitimate to withdraw life-sustaining treatments, including mechanical ventilation, when they appear futile and when they merely postpone death transiently, then the question arises: is there a difference between a brief postponement (such as, for example, the case of an anencephalic infant), a more substantial prolongation of life (such as an infant with trisomy 13 or 18 and major cardiac or gastrointestinal malformations) and

keeping alive for much longer periods of time an infant with inevitably lethal conditions (such as, for example, spinal muscular atrophy or progressive, irreversible neuromuscular paralysis)? In such situations the issue of 'proportionality' becomes crucial as it is not only the 'length of additional survival' that matters, but rather its 'quality', that is, the burden and amount of suffering that is imposed on the patient.

Prognostic uncertainty is often quoted as a major reason for continuing treatment; statistical probabilities, it is often said, do not apply to the individual. This is, however, a false justification. Better scientific knowledge, availability of sound epidemiological data, and of increasingly reliable diagnostic and prognostic tools have substantially reduced the margin of error in diagnosis and prognosis. Absolute, 100% certainty cannot always be achieved, but this holds for the great majority of interventions that we apply in everyday clinical practice, and it cannot therefore be a justification for not making a decision one way or another. Indeed, in ethical issues *not deciding* is in itself *a decision*, whose consequences should be evaluated and accounted for. On the other hand, when the situation is characterized by a significant margin of uncertainty, it may be wise to start mechanical ventilation and allow time for the acquisition of further information so that the decision to withdraw care will be based upon firmer grounds.

One possible approach to the issue of withdrawing mechanical ventilation in the NICU has been proposed by Tyson et al. [29] for preterm infants of marginal viability. These authors suggest that in those circumstances medical interventions should be judged on a case-by-case basis as *mandatory, optional, investigational or unreasonable*. 'Mandatory' is any treatment which has a very high probability of providing a significant net benefit to the patient; the physician has the moral and legal obligation to provide it, independently from the parents' position. In contrast, when treatment is futile, in the sense that it cannot change the ultimate poor prognosis, its continuation can be deemed 'unreasonable'; mechanical ventilation and other invasive and painful procedures which provide no real benefit and inflict useless suffering should be discontinued. When parents disagree, time can be allowed for them to accept the situation and come to terms with it; however, the welfare of the patient should always be the leading consideration. 'Optional' applies to situations where the risks are very high and the expected benefits uncertain or clearly very low. In those cases Tyson et al. maintain that the parents' views on initiation/continuation of intensive care and mechanical ventilation should

be explored and accepted. This view has also been supported also by Silverman [30], who highlighted the opportunistic considerations which may underlie decisions made by neonatologists to continue treatment [31]. The 'mandatory' category from one side, and the 'unreasonable'/'optional' from the other closely resemble the terms used by ethicists: obligatory versus nonobligatory [6]. Of greater interest is the last category suggested by Tyson et al. The term 'investigational' treatment refers to those situations where the ultimate effects of treatment are unknown or unproven. When this is the case, one might tell the parents that the proposed intervention is so new or its effect in this kind of patient so unproven that it should be considered an 'innovative' or 'experimental' procedure. It should be understood that in these cases both the parents and the physician do not really know what will happen and therefore they proceed on the basis of hypothesis and hope. It is necessary that both the parents and the physician assess and reassess continuously every subsequent step and that if there is evidence that the hypothesis was wrong and the hope unrealistic, they are prepared to stop the 'investigation' and withdraw the treatment. It should also be clearly understood that investigational treatment pertains to the area of human experimentation, requiring at a minimum written parental informed consent and careful evaluation and reporting of results, both favorable and unfavorable. A preliminary (if time allows) or retrospective assessment by an Ethics Committee is also recommended.

In any case and independently of the decision made, great emphasis must be placed on the need to alleviate pain and discomfort for the patient, even when sedation or analgesia might shorten life, and at the same time on providing adequate psychological and emotional support to the parents. This is easily said but not equally easily done [32]. The identification and quantification of pain and its control may be difficult in newborn infants and require special training and specific expertise on the part of doctors and nurses [33, 34]. Parental support should involve other professional figures and it should not be limited to the short periods of time immediately preceding and following the infant's death, but should also be offered afterwards to facilitate the mourning process [33, 34]. In our opinion, this aspect of neonatal care is not sufficiently developed in many NICUs. 'Palliative care' is not just providing sedation or analgesia to a patient who may eventually die; it requires a holistic and extensive team approach to relieving the physical, psychological, emotional, spiritual and social suffering of the dying infant and the family. It is, therefore, a complex task which requires

an interdisciplinary approach, extensive training and a major change in the entire milieu of the NICU [34].

### **The Role of Parents**

When decisions about withholding and withdrawing respiratory assistance are thought of as purely medical, physicians would appear to be the most appropriate surrogate decision-makers. At best parents receive, together with relevant medical facts, the neonatologist's assessment of whether intensive or palliative care is indicated, and are asked for their 'informed consent', a process which has been described by Anspach [35] as 'producing assent' rather than real sharing of responsibility for decision-making. In some countries and NICUs the whole process takes place implicitly and parents are informed simply about the consequences of decision-making rather than about its occurrence and contents [36, 37].

Ethical decisions, however, are not merely medical decisions. Rather, two components may be identified. The first has to do with the medical facts: diagnosis, prognosis and outcome. The second, as very well described by Leuthner [38] in his commentary on decisions regarding resuscitation of the extremely premature infant, concerns the meaning of such facts: the effect they will have on the life of the patient and of others involved, the extent they can be accepted and sustained, and the strategies that will have to be put in place to cope with such facts in the long term. While the first component of ethical decision-making is or should be as objective as possible, the second one is rather subjective, as it has to do with the values attached to the objective facts. But if decision-making has to include values, of course the values of the physicians are not necessarily better than those of other people; in particular, they are not necessarily better than those of the parents [35].

Traditionally and by law, in most countries, parents are entitled to make decisions on behalf of their children [39]. Given their bond of affection with the babies, and because they are the ones to whom the consequences matter most, parents are also generally regarded as the legitimate surrogate decision-makers for ethical decisions. However, parents cannot make decisions that jeopardize the baby's welfare, nor can they ask for illegal actions. When a clear medical indication exists regarding either treatment or nontreatment, and the best interest of the infant is clear, the physician's opinion should prevail to the point of overriding, in the case of conflict, the parents' wishes through a Court order.

There may be situations, however, when conflicting opinions between parents and physicians reflect a genuine difficulty in the identification of which is the best interest of a baby, and whether or not the proposed interventions will represent a disproportionate burden in the light of the expected benefits. In such situations, which can be identified within the 'optional' treatment category proposed by Tyson et al. [29], Leuthner [38] advocates a 'negotiated' model of shared decision-making in which 'the physician, using his/her medical expertise, guides the family through the decision-making process based on their value system'; thus the physician, while providing the medical knowledge, requires the parents' knowledge and values to determine which actions are in the best interest of that particular infant. This implies forming a partnership with the parents, listening to their concerns and perspective, offering our medical recommendations, and finally 'negotiating' together with them the meaning of their child's best interest.

The parents should never be left alone with the burden of decision-making [40]; however, the argument should not be used as a reason for restricting the information given to them and undermining their role as decision-makers [36, 37]. The available research does not support the idea that participating in decisions is harmful to parents; rather, those who played a more active role report less subsequent problems such as anger, depression, sleeping difficulties, loss of appetite and wanting to be left alone [41, 42]. According to Anspach [35], postdecisional regret is more likely to arise when parents are not given sufficient information, or enough time to evaluate the possible alternatives. More recently, the majority of parents of NICU patients interviewed by McHaffie et al. [43] viewed ethical decision-making on behalf of their babies as part of their parental responsibility; they clearly indicated they wanted to be given the opportunity and means for making decisions, and appeared to be able to do so without adverse sequelae. Being given the opportunity of making decisions, however, is different from being required or forced to do it; as pointed out by Harrison [44]: 'parents who do not wish to participate in decision-making should have the option of delegating decisions to a physician of their choice'.

## Conclusions

Since the original paper published in 1973 in the *New England Journal of Medicine*, where Duff and Campbell [45] admitted that 14% of all neonatal deaths in their

NICU were due to withholding or withdrawing treatment, many subsequent publications have shown a progressive increase in frequency of this phenomenon, to 30–60% of all neonatal deaths in the eighties [46–49] and up to 80–90% in the nineties [50–53]. Therefore, the decision to limit or to withdraw life-saving, but also invasive and painful procedures, in severely compromised or extremely preterm newborn infants has become common practice in modern NICUs and the way it is utilized has profound consequences on the final outcome of the babies we are caring for. For example, the results of neonatal intensive care in preterm infants at the limits of viability could be very different depending on the policies in use: better survival but also a higher incidence of disabilities in those units that were very aggressive in treating these infants; a higher mortality but also a lower incidence of disabilities among survivors in those units that were more permissive towards withholding or withdrawing treatment [54].

The question then is how best to honor this relatively new responsibility that we have, considering all the components of a rather complex scenario: the patient and his/her parents and family, the physician, the nurses and other components of the care-giving team, the society with its expectations, its moral values and legal obligations.

One must also consider the critical position of neonatologists regarding the feelings and reactions that their decisions of life and death in severely compromised infants can induce in the public, also because it is expected that physicians should be able to provide a satisfactory answer in every case: sometimes magic solutions, when the medical institution is idealized as capable of performing 'miracles'. Physicians, nurses, psychologists, social workers and other professional figures are generally prepared to perform different, sometimes overlapping, tasks such as making the diagnosis and the choice of treatment, providing continuous everyday care of the patient and supporting the family in facing the human and social problems associated with the disease and hospitalization, respectively. It is, therefore, necessary that all these components, together with the parents, and with full reciprocal respect of one's values and ideologies, collaborate in making a shared decision, that should take into account the choices and interests of the baby and his/her family [10, 55] and at the same time comply with an ethically correct methodology [56, 57].

In the NICU it may not always be possible to clearly identify a position that is totally appropriate and satisfactory, considering the four most important values of bio-

logical life, parental authority, the infant's best interest and the human being. Therefore, neonatologists must consider the possibility of making imperfect or even fallible solutions. This may be disturbing in the present era of 'evidence-based medicine', where it is recommended that clinical decisions be made on the grounds of solid scientific evidence and undoubted proof of efficacy. However, there is no alternative and we must learn to live with doubt and uncertainty, to value the merits of compromise, to admit the possibility of erring, but at the same time to be capable of using our mistakes for making improvements [58]. In this regard it is of utmost importance that we continue to discuss these problems explicitly and

in practical terms. Indeed it is only through an open debate, with the active participation of both professionals (physicians, nurses, bioethicists, philosophers and legal experts) and parents and the public in general, that we might be able to limit the impact of isolated cases, when they reach the mass media, and at the same time to build a solid basis for a much needed consensus.

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