‘DO NOT RESUSCITATE ORDER’ IN NEONATOLOGY: AUTHORITY RULES

Ethical dilemmas in medicine should be resolved in light of four essential principles. To specify and guide concrete actions, it is necessary to ‘supplement’ these principles by certain other (substantive, authority and procedural) rules. The purpose of this paper is to establish and justify the authority rules regarding the order not to resuscitate newborns. The authority rules are intended to indicate who should decide, but they do not determine what should be chosen. Decision regarding newborn’s treatment/letting die depends on medical and quality-of-life judgments. Parents, doctors, and society are considered to possess decisional authority in the matter. However, who in a given case should decide ought to be inferred from the reasoning which assumes, as its premises, the medical and quality-of-life judgments. The ‘logical’ syntax of this reasoning is presented in this paper.

Key words: authority rules, do-not-resuscitate-order, newborns, principlism

INTRODUCTION

When in the early 1970s bioethics emerged as a new, separate branch of knowledge, it was necessary to determine whether this discipline should have been grounded exclusively in the deontological tradition of medicine or in more general philosophical (ethical) theories (1). The first option seemed to have special appeal to these bioethicists who had their formal education in medicine and very often practiced as physicians. The second option was preferred by philosophers who dedicated themselves to resolving the moral dilemma of the contemporary medicine. Although eventually ‘the philosophical approach to
medical ethics’ has dominated bioethical discourse, it soon became evident that moral theories needed serious reconsideration to be useful for medical ethics. The ‘classical’ ethical theories (in particular, utilitarianism and Kant’s deontological ethics) proved to be so complex and awkward to be helpful in solving the moral problems of the medical practice and bio-medical research.

The ‘four principles approach to medical ethics’, called also ‘principlism’, could be regarded as the philosophically grounded bioethical theory which comes up to ‘practically’ oriented bioethicists’ expectations. Firstly, principlism seems to be enough simple, both in its conceptualization and application, to be effectively used to resolve moral dilemma in everyday medical practice (1). Secondly, it is a sufficiently wide ethical theory to be used in the pluralistic society. And thirdly, the ‘four principles approach’ to bioethics is in agreement with the dominant, at least within the West world, intellectual culture (2). Principlism reflects liberalism and individualism (1) which seems to be still the mainstream of this culture and accepts the ways of reasoning which are appropriate for this culture (3). No wonder, that this theory became the dominant ethical framework for resolving moral dilemma in medicine just in the 1980s, and the landmark book ‘Principles of Biomedical Ethics’ by Tom L. Beauchamp and James F Childress was – as Callahan observes – “by far the most popular medical ethics textbook in the 1980s and 1990s for classroom use (and probably still is)” (1, p. 287).

Principlism is based on the assumption that all ethical dilemma should be resolved in the light of nonabsolute (prima facie), middle-level principles which are derived mainly from so called ‘considered judgment’ in the common morality. Respect for autonomy, nonmaleficence, beneficence, and justice constitute the four clusters of principles.

To specify and guide concrete actions it is necessary, however, that the cluster of four principles would be ‘supplemented’ by certain moral rules, which could be divided in three groups: substantive, authority, and procedural rules (2). Substantive rules could be considered as the rules which specify the abstract principles. The authority rules indicate who should perform a certain action. Among this type of rules one can distinguish: (i) rules of surrogate authority (who should decide in the name of an incompetent person); (ii) rules of professional authority (who is authorized to make decision whether the patients’ decisions should be accepted or overridden); (iii) rules of distributional authority (who is the proper person to decide on the allocation of medical resources). It should be emphasized that substantive and authority rules “interact in both theory and practice. For instance, authority rules are justified in part by how well they express substantive rules and principles” (2, p. 39). The third group of rules, procedural ones, regulates distribution of medical resources, in particular, in the situations when both substantive and authority rules cannot help sufficiently. The main purpose of this article is to establish and justify the authority rules regarding to the ‘do-not-resuscitate’ (DNR) order in neonatology. Taking into
account that justification of authority rules assumes reflection on the proper, from a given point of view, substantive rules, the standard of “patient’s best interest” will be discussed.

METHODS

In this study, coherentism as a method of justification in ethics is accepted. This method consists of four essential steps: (i) identification of ‘considered judgment’ in the domain of common morality; (ii) specifying and (iii) balancing it (if in conflict with other considered judgment(s)), and (iv) testing if the ‘reflective equilibrium’ was yielded. It should be accentuated that considered judgments even if considered as ‘fixed points’ are always subject to change, and the obtainable reflective equilibrium is never complete, i.e., that in practice some degree of incoherence within reflective equilibrium should be allowed.

RESULTS AND DISCUSSION

Undoubtedly, neonatal mortality in the developed countries has significantly decreased in the last decades (4, 5). Advances in obstetric and neonatal care together with the establishment of centers capable of providing highly sophisticated cure and care have greatly improved the survival chance of progressively smaller and less mature neonates (4). Unfortunately, despite this impressive progress, outcomes for, in particular, extremely premature (gestational age \( \leq 24 \) weeks) and incredible-low-birth-weight (ILBW; \( \leq 750 \) g) infants are still very poor. They are at a significant long-term risk of chronic medical problems and neuron-developmental sequelae (4, 6-8). It should not be forgotten that the medical procedures are often highly aggressive in their manner and are the source of iatrogenic pain, i.e., related to diagnostic and therapeutic processes (so called procedural pain), and to painful long-term results of medical treatment. Highly sophisticated procedures of contemporary neonatology unfortunately can serve as very clear examples of actions which cause both procedural pain and painful long-term follow-up results (9-16). Moreover, it is worth noticing that in the case of neonates the procedural pain is experienced in the period of newborns’ very intensive neurological development. This permits to assume that the experience of (procedural) pain itself would have potential long-term effects in the following babies’ development (16-19).

The question arises of whether the same categories of the newborns (ILBW, extremely premature) really benefit from progress in medicine, or rather they should be considered the victims of this process. Is it morally acceptable to withdraw or withhold newborn’s treatment? Or, is it an ethical duty to stop aggressive therapy?

The data obtained in empirical studies seem to reveal that during last decades the conviction that it is morally acceptable or even morally desirable to let
extremely premature/sick infants die has gained acceptance in the different societies (8, 20). This conviction is in coherence with the well-known from the tradition of medical ethics maxim: “Primum non nocere”. This rule is closely associated with the principle of nonmaleficence, which is thought to be a considered judgment (2).

The study carried out by Schulz-Baldes et al (8) which aimed at investigating the end-of-life practice in one of large perinatal centers in Germany clearly showed that 81% of neonatal deceases of newborns in delivery room and 83% in the neonatal intensive care unit were preceded by a decision to withdraw/withhold life-sustaining therapy. In 79%, death occurred as a direct effect of withdrawing the mechanical ventilation. DNR order seems to be the main means by which the end-of-life-decision is realized.

Decisions, especially end-of-life-decisions, regarding treatment of newborns are particularly difficult from the ethical point of view. The newborn is not and has never been competent person/patient. The surrogate decision is needed. However, it should be emphasized that the guidance rules for surrogate decision-making in the case of newborn are substantially different from rules used in the case of formerly competent patients. Different ethical and legal standards which can be applied in the case of actually incompetent patients who, however, were formerly competent (for instance: ‘advance directives’, ‘substituted judgment’) are simply inapplicable to the decision-making process regarding newly born babies’ treatment (2, 21). De facto, the only option is to use ‘the best interest standard’ in its form known as ‘Barber’ (21). This standard assumes that when deciding whether treatment or withholding/withdrawal treatment (in particular acting according to DNR order) is in the newborn’s best interest, five factors should be taken into account. “First, does the medical treatment offer relief of all suffering or does it merely prolong inevitable dying? Second, will medical treatment allow the infant to enjoy optimal functioning? Third, what quality of life can be predicted for the baby? Fourth, what is the predicted lifespan of the child? And last, how will medical intervention affect the parents and family of the baby?” (21, p. 55). Beauchamp and Childress find the last factor objectionable. They agree that it is rather common that patients have an interest in their families’ welfare; however, they simultaneously find unjustifiable “to impute altruism – a desire to relieve family of its burdens – to the patient against his or her medical best interests” (2, p. 217). In fact, problem seems to be even more complicated. Even if the most patients have an interest in the well-being of their families, it remains unclear and uncertain if the patients and the members of their families understand in the same way what constitutes ‘good’ and what ‘evil’ for family’s welfare.

The ‘best interest’ standard can be considered as a substantive rule in light of which the authority rules (who should make a decision regarding newborn’s treatment?) ought to be justified. Beauchamp and Childress (2) observe that a surrogate decision-maker should be characterized by four essential qualifications:
● Ability to make reasoned judgments (competence);
● Adequate knowledge and information;
● Emotional stability;
● A commitment to the incompetent patient’s interests that is free of conflicts of interests and free of controlling influence by those who might not act in the patient’s best interests” (2, p. 244).

The last of the above listed qualification seems to be particularly interesting. It should be accentuated that this qualification assumes partiality of surrogate decision-makers rather than they impartiality. It means that surrogate decision-makers should act as an advocate rather than as a judge. Although three previous qualifications seem to predispose a physician to be a decision-maker, the fourth qualification speaks in advocacy of parental right to be the primary decision-makers in the name of their children, including neonates. In fact, parents seem to be the persons who proved their engagement in favor of newborn by taking actions which ultimately resulted in the birth of the infant. Moreover, the common morality assumption permits to consider the parents as the people who seek their children best interests in the highest degree. However, neither does it mean that a physician should be excluded from the decision-making process, nor that parents’ decision has always to be honored. Taking into account that in this decision-making process human life is at stake, just another party, namely a state and its authorities, should be involved in this process. The primary purpose of a state is to protect its citizens, especially their right to life.

The first step in the decision-making process is based on deciding whether - taking into account medical condition of the newborn - a given treatment, in particularly resuscitation, should be considered as ‘indicated’, ‘optional’ or ‘harmful/futile’ one (2). By ‘medically indicated treatment’, the treatment is understood which, in all probability, causes the amelioration of the life-threatening condition of the neonate. ‘Optional treatment’ is defined as treatment which in fact only prolongs dying of an infant who is chronically and irreversibly comatose. This treatment ought to be neither painful nor particularly expensive. The fact that optional treatment is painless and relatively cheap differentiates it from ‘harmful/futile treatment’.

A physician seems to be the right person to undertake the decision about to which group a given treatment belongs. It is worth noticing, however, that the physician’s decision is not ‘purely’ medical in its character. To classify a given treatment into one of the three groups, the physician always, in the more or less conscious way, presupposes the axiological dimension of medicine, in particular ‘quality-of-life’ judgments (2). The axiological judgments are justified on the basis of physician’s outlook of life, accepted philosophical or religious convictions and not by ‘purely’ scientific knowledge of medicine. In fact, it is highly doubtful whether ‘purely’ scientific judgments exist at all in the medical practice (22).

It is physician’s responsibility to check that parents fulfill the qualifications (indicated above) necessary for the surrogate decision-maker, namely whether they
are competent, in possession of the adequate knowledge and information, emotionally stable, and able to act freely, i.e., without controlling influences that determine their action. It is physician’s duty to convey to parents relevant and reliable information about their infants’ medical conditions (to a degree they want to know) and to take care of parents’ - including emotional – wellbeing. It is possible, however that despite all physicians’ efforts, the parents do not possess necessary qualifications to be recognized as the right persons to make a surrogate decisions. In this case the doctor duty is to refer the case to the appropriate state’s authorities.

The third step is also the last one in the majority of cases. Parents decide if the DNR order ought to be implemented. The available studies reveal that in the majority of cases parental decision is in agreement with physician’s opinions, i.e., parents decide that their infant should not be resuscitated when such treatment is defined by the doctors as harmful/futile, and when resuscitation is considered to be the medically-indicated treatment they authorize the physicians to resuscitate their infant (8, 20). If resuscitation is considered to be an optional treatment, the parents’ decision should be always respected. It seems that it is the only one exception to these rules. The state has a moral power to decide how the scarce medical resources will be used. Beauchamp and Childress (2) indicate, as an example which appears in neonatal intensive care unit, the decision regarding withdrawing extracorporeal membrane oxygenation (ECMO) from a newborn with poorer prognosis in favor of another with a better prognosis. The state duty is to protect their citizens’ lives by using the scarce resources in the most efficiently way.

When disagreement between the physician and the parents occurs it is necessary to introduce the additional authority rules (step fourth). As it was indicated above, such disagreement can take place only when the treatment is defined as indicated or harmful/futile. Firstly, the parents can decide to implement DNR order in the situation when the resuscitation is considered as the indicated medical treatment. Depending on the circumstance, the physician can refer to the state’s authorities or, in emergency, act according to the standard of so called ‘justified paternalism’. Beauchamp and Childress, quoting the court decision (“In re Estate of Dorone”), observe: “The necessity to preserve life outweighed third-party judgments about what an unconscious patient would want. The court held that in emergency situations calling for immediate action, «nothing less than a fully conscious contemporaneous decision by the patient will be sufficient to overrule evidence of medical necessity»” (2, p. 131).

Secondly, it is imaginable that the physician who has decided that resuscitation is the medically indicated treatment, stands - against the parents’ decision - to enter DNR order. In this situation, however, it is presumable that the physician is motivated by external and probably immoral reasons.

Thirdly, parents can decide to resuscitate their infant against the opinion of the physician who claims that - in a given situation - such treatment ought to be considered harmful or futile for the infant. The physician has moral right to refuse to undertake resuscitation. This right is justified by the judgment that none can be
forced to do something against his/her conscience (right to the objection of conscience).

Fourthly, it is possible that the physician opts for undertaking/continuing resuscitation even if it is considered harmful/futile treatment and against parental authorization to withhold/withdraw it. As Schulz-Baldes at al (8) show, the physicians seem to be prone to act according ‘wait until certainty’ standard. In consequence, end-of-life decisions, including DNR order, are generally taken relatively late. It is quite likely that ‘wait until certainty’ standard contributes to increasing and prolonging newborns’ pain experiences. In order to avoid newborns’ pointless suffering Young and Stevenson (6) propose an alternative, called ‘individualized prognostic strategy’ standard. When disagreement between the physicians and parents exists regarding which of these standards should be implemented, it seems useful to refer to the appropriate social or state’s institutions: to the hospital’s bioethics committee and/or to the court.

Conclusions
1. The progress in medical knowledge and practice has led to the situation in which patients become victims of medical success. It seems to be particularly obvious in the treatment of extremely immature and sick newborns.
2. The respect for newborns’ human dignity obliges parents, physicians, and the appropriate state institutions to reconsider their attitude toward the end-of-life-decisions in neonatology, including the DNR order.
3. The ‘best interest’ standard should serve as a guidance rule for surrogate decision-making regarding the DNR order in neonatology.
4. The authority rules indicate the parties which ought to be involved in making end-of-life decisions: newborns’ parents, physicians, and state authorities.
5. The primary decision-maker should be infant’s parents.
6. State authorities could override the parental decision only in two cases: (i) when parents authorize the DNR order in the situation in which resuscitation is considered to be ‘medically indicated treatment’ and (ii) when the problem of the allocation of the scarce medical resources arises.
7. The physicians’ primary role in end-of-life-decisions is to be a parents’ and state authorities’ advisor.
8. Neither parents nor state authorities’ decisions cannot deprive physicians of their right to the objection of conscience.

REFERENCES

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