

## Principlism and Neonatology: Utilising The Principles of Medical Ethics in Decision-Making for Neonates

Mark Tan Kiak Min

Faculty of Medicine, Universiti Teknologi MARA, Sungai Buloh, Selangor, Malaysia

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### Corresponding author:

**Mark Tan Kiak Min,**

Medical Ethics & Law Unit,  
Faculty of Medicine,  
Universiti Teknologi MARA,  
Sungai Buloh Campus,  
Jalan Hospital, 47000  
Sungai Buloh, Selangor,  
Malaysia.

Email: drmark.medethics@gmail.com

### ABSTRACT

Prematurity is the leading cause of infant mortality and one of the main reasons for newborn infants to be admitted to the Neonatal Intensive Care Unit (NICU). Advancements in medicine has made the NICU a maze of sophisticated modern technology and expensive to run. These advances in technology have also resulted in an added layer of complexity to many ethical dilemmas that are encountered in the NICU. In 1977, Beauchamp and Childress introduced the principles of biomedical ethics. These four principles of (1) respect for autonomy, (2) non-maleficence, (3) beneficence and (4) justice, form a suitable starting point for the analysis of the moral challenges of medical innovation. This article explores how the four ethical principles relate to decision-making in the NICU, and how they can be applied to the treatment of sick newborn infants in clinical practice. It also highlights the reasons why healthcare personnel need to equip themselves with good communication skills and up to date knowledge of ethical considerations in the NICU in order to make quality decisions about care for their patients. This article also suggests that a Clinical Ethics Committee can play a vital role in ensuring that the best decisions are achieved for these patients.

**KEYWORDS:** Medical ethics, principlism, neonatology, prematurity, clinical ethics

### INTRODUCTION

While the majority of childbirths result in a relatively healthy newborn infant, the World Health Organization (WHO) estimates that every year, about 15 million babies worldwide are born preterm and this is the leading cause of infant mortality [1]. In 2013, 7% of all live births in England and Wales were preterm births, and 99% of births “under 22-weeks and weighing less than 1,000g” lead to an infant death while this rapidly decreased to 41% for live births at 24-weeks gestation and to only 1% at 34-weeks gestation [2]. In Malaysia, preterm births during the same period accounted for 12.3% of all births, while the mortality rates for infants born at 24-weeks gestation stood at 84.5% and decreased to 8% at 31-weeks gestation [3]. Many of these preterm newborns would have required admission to a Neonatal Intensive Care Unit (NICU) for medical care.

When this occurs, parents who have just celebrated giving life to a newborn are faced with the possibility that this same infant may die. Important decisions need to be made both by the parent(s) and

the healthcare team, most of the time on an *ad-hoc* basis [4, 5]. Unfortunately, this becomes “an area of medicine where emotions cannot be detached” and while guidelines and standards have been developed to help with decision-making, it is still hard to envisage navigating the variety of challenges and uncertainties encountered in the NICU [6]. This is especially true when put in context of a virtually unlimited healthcare need with limited healthcare resources [7].

### Neonatology and the NICU

Neonatology is the area of medicine dealing with the care of sick newborn infants and is a relatively recent field in medicine. Up until about 60 years ago, there was not much that could have been offered to an ill newborn. In fact, most efforts were limited to providing some supplemental oxygen and maintaining the infant’s body temperature: what would now be thought of as comfort care [8].

Three significant milestones kick-started research into practices that improved infant mortality: the description of the “Apgar Score” in 1952, the

opening of the first NICU in 1965 in New Haven, and the establishment of neonatology as a sub-specialty in 1975 [9]. This improved survival rates so much so that many parents who would have been mourning the loss of a child not too long ago, are nowadays taking delight in their newborns albeit sometimes with severe and long-lasting disabilities [6]. On the one hand, subsequent developments such as the invention of the ventilator, the perfecting of artificial nutrition and hydration with total parenteral nutrition (TPN) and cardiopulmonary resuscitation (CPR) techniques, the discovery of surfactant for lung maturation, and further improvement of these machines and techniques have also significantly improved our care of these patients [8]. On the other hand however, all these advances have also resulted in an added layer of complexity to many ethical dilemmas that in the past simply took care of themselves because the babies were too frail and weak to survive [8].

Today's NICU is a maze of sophisticated modern technology, and it is estimated that the National Health Service (NHS) spent up to £1,200 per infant per day in 2009 to treat these infants who were admitted to the NICU [10]. While data on the cost of running an NICU in Malaysia is scarce, a study in 2005 reported that the total cost of treatment of a preterm infant in NICU ranges from 26 to 3818 US Dollars [11].

There are three groups of newborns generally who are admitted to the NICU [7]. The first are full-term babies with acute illnesses. These infants include those who have encountered some complications during childbirth resulting in hypoxic-ischaemic encephalopathy and those with sepsis. The second are babies with congenital anomalies such as those with congenital malformations such as anencephaly or a myelomeningocele or cardiac anomalies, or a genetic disorder such as Tay-Sachs, or Down's Syndrome. The third group consists of those with extreme prematurity.

Each of these groups of infants, in addition to the variety of abnormalities and treatment options, pose different ethical challenges to decision-making by parents and physicians aiming to do their best for these severely compromised newborns as there is no one standard solution to their unique problems. Adding to

this problem, the ratio of consultant neonatologists to neonates in Malaysia is approximately 1:60-70. These physicians not only need to ensure that the medical needs of the neonate is taken care of, but they also need to manage the needs of the parents, and the healthcare system in attempting to resolve ethical dilemmas that arise. As such, let us now explore how decisions on some of "the most complex and multifaceted dilemmas in all of medicine" can be made in reference to the framework of the following ethical principles [7].

### **Ethical principles**

Ethical dilemmas that arise in the course of caring for a patient often evokes powerful emotions and strong personal opinions on how to resolve the issue at hand. However, these emotions and opinions, no matter how eminent they are, do not provide a satisfactory way of resolving ethical dilemmas in clinical practice. Hence a range of ethical systems have been proposed and utilised over time to form the basis of ethical decision-making [12].

One such form is known as utilitarianism and was propounded by Jeremy Bentham. Utilitarians view that the morality of an action is based on their utility or usefulness to the majority of people. This view is often simplified to the maxim of "the greatest good for the greatest number of people" or by "maximizing pleasure and minimizing pain" [13].

Another system emphasizes the development of traits or virtues. Virtue ethics, as this is known, argues that the development of these virtues such as courage, truthfulness, wisdom, etc. enable the person to become someone who will be able to make right decisions. The balancing of virtues by applying the Golden Mean such as that which was proposed by Aristotle still plays a part in decision-making, albeit in a modified manner, and will be illustrated later in this article. In addition, virtue ethics concerns itself with the effects of moral action, not only on those affected by them but also on the moral agent [13].

In more recent times, new attempts have been made to introduce ways to solve ethical decisions through analysis. In 1977, Beauchamp and Childress published the first edition of the book *Principles of Biomedical Ethics* [14]. This book, currently in the

seventh edition, described a set of four moral principles that is also known as “principlism” and are currently the most widely taught principles in medical schools globally [14]. As such, the principles of respect for autonomy, non-maleficence, beneficence and justice, which are derived from common morality, form a suitable starting point for our analysis of these “moral challenges of medical innovation” [15].

### Respect for Autonomy

Autonomy, originally described as the self-rule of independent city-states, is now one of the most championed principles in medicine and is commonly used to refer to individual autonomy [16, 17]. This is unfortunate because what was meant to be a concept has instead been turned into the principle, whereas the original principle- that of ‘respect for autonomy’, has been less understood.

Two conditions are essential for a person to have autonomy: *liberty* (independence from controlling influences) and *agency* (capacity for intentional action) [14]. Meanwhile, the principle of respect for autonomy acknowledges the rights of autonomous agents to choose freely and accept responsibility based on their values and beliefs and can be stated as both a negative and a positive obligation [17].

This has only *prima facie* standing, and competing moral considerations can sometimes override this principle. Most importantly, Beauchamp and Childress viewed that “obligations to respect autonomy do not extend to persons who cannot act in a sufficiently autonomous manner, and who cannot be rendered autonomous- because they are immature, incapacitated, ignorant, etc.” [14]. This would seem then, that newborn infants would not be accorded respect for autonomy because they have never been autonomous in the first place. Nonetheless, it does not mean that they should not owed moral respect. Other ethicists like Miller have argued that while the newborn does not have autonomy, surrogates who usually possess a special relationship with the newborn are granted the authority to make decisions for them, and that the “respect for autonomy” principle does apply [18]. He however acknowledges that this respect for autonomy is not without limit, and that decisions

have to be made based on a duty to act in the best interests of the child- a topic that will be discussed later in this paper [18].

“Parents nowadays play a central role in decision-making about their children and it is no longer generally assumed, or asserted by the medical profession itself that doctors know best” [6]. This task becomes arduously difficult, especially as one has to deal with the emotions of fear and uncertainty that are cast over the future of their own child while making decisions. Physicians on the other hand have a duty of care to their patients- to preserve life where and when they can, but are certainly not obligated to provide life-sustaining measures if the treatment is one of futility [19].

In the context of respect for autonomy then, physicians have to work on one hand with having a responsibility to protect the best interests of the patient, while on the other hand having to respect the autonomous choice of the surrogate. This sometimes results in conflict as there will be different pressures and prejudices that influence the decisions of both parties, and the physician’s duty may be in conflict with parental wishes.

One argument put forward is of how the surrogate knows what the neonate feels, or wants, especially if the neonates have never been able to communicate this in a comprehensible way. Are the decisions made based on what the surrogate thinks they feel or want, and if they are made in the best interests of the patient, how does the surrogate know what the interests of the infant really are? Would the decisions then be made based on an assumption or based on what the surrogate wants for the infant?

An ethical conflict arises when parents request to forgo treatment which are readily available and effective in relieving the condition such as in neonates with chromosomal disorders (for example duodenal atresia in a neonate with Trisomy 21) or a neonate with a severe congenital malformation whose treatment entails multiple operations and life-long care with yet uncertain long-term outcomes (for example in complex cardiac malformations).

In order to understand how difficult and complex some of these decisions are, it would be

pertinent to explore a little more about surrogate decision-making. It may be correctly argued that the most appropriate standard to apply to surrogate decision-making in the NICU are that of “best interests as judged by the best estimate of what reasonable persons would consider the highest net benefit among the available options” [14].

When making a decision based on best interests, a surrogate makes it based on determining the highest net benefit amongst all the choices available. Despite considering the best interests of the infant being paramount, one must not discount the interests of others, including the stress of the parents, and their capabilities to take care of the infant should he or she survive with severe disabilities, in the context of quality of life considerations such as the availability of social, educational, psychological, and economic support [18].

As such, the Nuffield Council on Bioethics’ guidelines suggest the importance of decisions that are made jointly by healthcare professionals and families based on shared comprehension [6]. However, they do acknowledge that at times it may be necessary to ask a court to decide what care is in the best interests of the baby. When this happens, most of the time it is due to a breakdown in communication between the two parties.

A pertinent example can be found in the 1982 case of Baby Doe in the United States of America (USA) [20]. In this case, Baby Doe was born with Down syndrome and esophageal atresia with a tracheoesophageal fistula that required immediate surgical correction in order to survive. However, the parents of Baby Doe decided to withhold their consent for the surgery and Baby Doe subsequently died. The Surgeon General of the United States opposed this decision because he was of the opinion that the parents had declined the surgery not because the risks of surgery outweighed the benefits, but because even if the anomaly was corrected (which it could), the baby would still be intellectually disabled. This led to the introduction of the Baby Doe Regulations in the USA that allowed the government to directly intervene in treatment options for neonates born with congenital defects.

It is a well-accepted fact that when communication is carried out effectively, it becomes a powerful tool that aids the decision-making process and conversely, poor communication can lead to devastating outcomes [21]. Decisions about care of the ill newborn take place through “an accumulating series of conversations, observations and interactions, sometimes quite minor, that contribute to a final decision” [6]. It is therefore important that parents are not deluged with conflicting information, and that the information given is comprehensible and not littered with medical jargon. They also need to feel that they have enough knowledge to make an informed decision and the information relayed was not selective of what the medical team wanted [22].

Learning from these experiences, many NICU’s have established a special room where discussions can take place in a comfortable, yet confidential manner. Many will also have arrangements in place for parents to visit and observe their ill infant and to take part in their care as well [23]. In addition to this, both the Royal College of Paediatrics and Child Health and the Royal College of Obstetricians and Gynaecologist have included communication skills as a mandatory part of the membership exams they conduct [24, 25].

Having explored how respect for autonomy determines who makes decisions for the sick neonate, in terms of surrogacy of autonomy and professional duties of care, and how despite acting in the best interest of a non-autonomous patient, conflicting decisions may result from a breakdown in communication; we now turn to the next two principles to realise how these can help us to make quality decisions for these patients.

### **Non-maleficence and Beneficence**

Non-maleficence obligates one to abstain from causing harm to others. Often the saying *primum non nocere* comes to mind. Abiding by this principle to ‘do no harm’ does not necessarily mean that our decision will be beneficial to our patients. Morality requires not only that we treat persons autonomously and refrain from harming them, but also that we contribute to their welfare [14].

Therefore, the principle of beneficence, or simply put as doing something good or beneficial for a patient, is also closely linked to non-maleficence. Beneficence is of course much more than that, and also deals with relieving, lessening, or preventing harm and providing benefit and balancing benefits against risks and costs [18].

Beauchamp and Childress traditionally described issues such as making a distinction between killing and allowing to die; of withholding and withdrawing treatment; and distinguishing between ordinary and extraordinary treatment in terms of non-maleficence, while issues such as surrogate decision-making; balancing of risks and benefits; and paternalism are discussed in view of beneficence [14].

A well-known part of the Hippocratic Oath states that “I will use treatment to help the sick according to my ability and judgment, but I will never use it to injure or wrong them” [26]. While non-maleficence and beneficence may seem to complement each other, they may also contradict each other at times. Furthermore, Beauchamp and Childress state that “while non-maleficence typically does override other principles, the weights of these moral principles vary in different circumstances and no one rule of ethics favours avoiding harm over providing benefit in every circumstance” [14]. This is easiest to comprehend by illustrating a case such as that of a neonate in the NICU who requires feeding via TPN, which may be a beneficial treatment. This would necessitate causing harm and pain to the infant when inserting the intravenous line. Would it then be wrong to insert the line, or would it be right to start TPN? This decision at hand can also be looked at from the perspective of ‘passive paternalism’, or denying requests for non-beneficial procedures. In this situation, it may be a clinically non-beneficial intervention, rather than futile one. It should not be performed not so much that it will harm the infant, but rather will not result in the benefit sought by the surrogate or physician [14].

Many healthcare professionals and family members feel justified in withholding treatment that was never started but not in withdrawing treatment already initiated. It is not uncommon to note orders in

patients charts in the NICU like ‘no further escalation of antibiotics, or ‘not for CPR’, ‘not to start inotropic support’, but orders such as ‘requested to stop ventilation’, ‘family requested to remove endotracheal tube (ETT)’ are rarely seen. Even if an agreed decision to withdraw treatment was made, it would usually be done in a staged fashion such as ‘not to change ETT when due’, or ‘not for intravenous line cannulation if line malfunctions’ or ‘not to restart/escalate antibiotics once current course is completed’. Why is this so? Could it be that the decision-makers did not want to feel that they caused the death, or that they felt more responsible for the death as a result of withdrawal of treatment rather than withholding it?

Beauchamp and Childress claim that this distinction between withdrawing and withholding treatment is morally irrelevant and potentially dangerous [14]. They argue that both withdrawing and withholding can be justified depending on the circumstances. This brings us to the next point of balancing.

Balancing is an exercise used in clinical ethics for decision-making and seems particularly well suited for reaching judgments in particular cases rather than in general situations. When making a decision, be it on withholding, withdrawing or even initiating treatment for the ill neonate, one should weigh the harms and the benefits of the treatment in the best interests of the patient. Does providing life-sustaining treatment to the newborn infant produce more harm than benefit and violate the principle of non-maleficence? At what point does treatment no longer bring a benefit, and at what point does it harm? These are difficult questions to answer as we have a difficulty in predicting, or prognosticating in neonates [27].

For example, if a 28-week preterm baby born with respiratory distress syndrome, intraventricular haemorrhage, necrotizing enterocolitis, and who has a very poor prognosis, now develops a catheter-related blood stream infection, would it be beneficial to start antibiotics? In reality, most physicians in the Malaysian NICU setting would probably consider the initiation of antibiotics, however if one were to base the decision on balancing, most would think that it would be ethical justifiable not to start antibiotic

therapy. This case illustrates the issues that are currently being faced and the need to utilise ethical skills such as balancing in making sound clinical decisions.

A further consideration that complicates our decision-making is that physicians do not have the luxury of working based on hindsight but instead recommendations are made based on experience and on a case-by-case basis [18]. As Wyatt aptly states “in different circumstances, and with different individuals, the balance between burdens and benefits will change” [28]. With research, advances in neonatology have greatly improved the survival of infants who are born severely premature. However, outcome in terms of neurologic impairment and intellectual function remain a prognosticative dilemma. For example, with the advances of scientific knowledge and the passage of time, providing oxygen therapy (considered standard therapy once upon a time) in premature neonates was found to have cause worse cases of retinopathy of prematurity. This heroic effort in saving extremely premature neonates could have lead to a lifetime of suffering especially in areas where there is a lack of social support.

This brings us to the concept of futility of treatment which typically refers to a situation where ‘irreversible dying’ occurs in the patient or that the patient is actively dying and no amount of whatever we do can stop this outcome. Unfortunately, this situation is complicated, as are the choices of treatment that come with it. Many ask the question ‘futile to whom?’ because what may seem to be futile to a physician, may bear a 1% chance of survival. To a parent, sometimes a 1% indicates a hope for a miracle to happen.

That being said, while there are situations in the NICU in which hope, of both the healthcare team and the family, is appropriate such as when the outcome of a surgery is uncertain. However, there are also situations where “hope should play no role, and where the language of hope is not only misplaced but also morally reprehensible”, such as when treatment is futile [29]. Finally, Flynn suggests that in addition to treating these newborns, beneficence means that the job of the NICU team is also one of education- to

educate those concerned about the diagnosis, possible treatment modalities and options, the risks and benefits of each as well as the prognosis of the condition as best they can.

## Justice

We now turn to the last ethical principle- justice. Justice as described by Beauchamp and Childress can be seen in the perspectives of equality of treatment based on what is due or owed to persons, and that of distributive justice, which deals with the equitable distribution of resources [14].

Equality of treatment dictates that persons should be treated equally. In our context, by virtue of being born as a human being, a neonate should be treated equally as any other human being, including adults. This means that they should be given fair opportunity, and should not be discriminated on when it comes to receiving healthcare.

More importantly though, is the debate of whether preterm neonates should be treated in the same way as full-term newborns if they have the same medical condition, even if the prognosis may differ? While based solely on the justice view, many may have to agree with this. Opponents often take the stand that a decision cannot be made solely on this basis alone, but also that of the other ethical principles and that of distributive justice.

In terms of distributive justice then, we should look at resource allocation. It is evident that running a NICU is expensive. Some people have even come up with the idea that these newborns are too expensive to treat, and the cost of running these units may threaten the overall welfare of society [7]. Some on the other hand, have suggested using part of the expenditure to set up neonatal palliative care units. Others suggest channeling resources taken from NICU care to fund prenatal care, in an attempt to avoid the causes of NICU admissions happening in the first place [7].

A criterion that is often used to justify this expenditure is based on that of Quality Adjusted Life Years (QALYs), a measure designed to measure cost effectiveness of various treatments [7]. While a discussion on this topic would be beyond the scope of this essay, it is worthwhile to mention that typically younger patients fare better than older patients in the

allocation based on this standard. It is based on this statistic that NICUs continue to be allocated a significant amount of the healthcare budget [18].

## CONCLUSION

We have explored how the four ethical principles relate to decision-making in the NICU, and how they can be applied to the treatment of sick newborn infants in clinical practice. While the society we live in today tends to overemphasise the use of ‘autonomy’ as the main principle of ethics, there are also other frameworks and principles of ethics not discussed in this essay that need to be given consideration.

The rapid advancement of medical technology promises further improvements in our care of sick neonates. While this takes place, the fact remains that no matter how much we improve, some of these neonates will still eventually die and quality ethical decisions will also become more complicated. As such, we need to accept the responsibility for the power we have obtained and ask the frightening question ‘what kind of life are we saving?’ [30].

Two essential components of quality end of life care are possessing an advanced directive and having conversations about it with our families so that our preferences are known when the circumstances arise [31]. Unfortunately, infants in the NICU can do neither of these. As such, healthcare personnel need to equip ourselves with good communication skills and up to date knowledge of ethical considerations in the NICU in order to make quality decisions for our patients. We need to recognise our roles as “choice architects”, the boundaries of “the zone of parental discretion”, and try to utilise shared decision-making as the approach when attempting to solve ethical dilemmas that arise in the NICU [32]. It would also be beneficial that a clinical ethics committee be established to assist clinicians in analysing and understanding these complex ethical cases as well as to make good and ethical decisions that benefit both the healthcare professionals, patients and their families. In the meantime, the words of Wyatt “If it is apparent that there is no hope of meaningful long-term survival, and that intensive support is merely prolonging the

process of dying, withdrawal of medical treatment, following full discussion and with the agreement of the parents, is most consistent with a genuine respect for the dignity of the individual” may currently seem to be the optimal path to thread [28].

## Conflict of Interest

Author declare none.

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