
THE ETHICS OF DNR ORDERS AS TO NEONATAL & PEDIATRIC PATIENTS: THE ETHICAL DIMENSION OF COMMUNICATION

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Case # 1

Angela is a 34-week neonatal patient born at 27 weeks gestation with a birth weight of 2 pounds. She has had a rough course in the Neonatal Intensive Care Unit. For the past two and a half weeks, Angela's saturation rate has been in the low thirties, forties, and fifties. Whether she is on high frequency ventilation or regular ventilation, there seems to be no appreciable difference in saturation rate.

Angela's 17-year-old mother and her grandmother want "everything done." Mother reports that she does not know who is Angela's father. What are the physician's options? What are the attendant ethical issues?¹

Case # 2

Jonathan Roland, an 18-month-old boy diagnosed with a rare form of pediatric cancer 4 months ago, is critically ill. Initial chest surgery and chemotherapy went well, but complications developed 3 months into treatment. His parents agreed to emergency surgery, even though Jonathan was at high risk for hemorrhaging because of the medications used for his cancer treatment. This complication did occur, and Jonathan went into shock. He was placed on extra corporeal membrane oxygenation (ECMO), but has not done well. Be-

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¹ I would like to thank Dr. Cheryl Vaiani for providing this hypothetical.

cause of swelling and infection, his surgical wound is open, and he remains at risk for bleeding, which greatly complicates routine care.

The medical staff disagrees about the propriety of placing Jonathan on ECMO, given his diagnosis of a cancer for which survival rates are very low and the risks imposed by chemotherapy drugs. One of the primary physicians asked to be removed from the case, explaining that Jonathan's care has been driven more by his father's unwavering insistence that "everything be done," than by sound medical decision-making and consideration of Jonathan's best interests. Some staff share this view, and several have expressed concern that, for Jonathan, the cure is worse than the disease.

Other staff members believe that medical judgment has been responsibly exercised. A consulting oncology specialist notes that few established standards exist for treating Jonathan's rare form of cancer. Therefore, while he agrees that the prognosis looks grim, he does not believe that the decision to continue ECMO is unsupportable, particularly if the parents understand the situation and wish to proceed.

At issue today is the parents' refusal of a DNR order. A family and staff conference is called, to which the physician-chair of the pediatric ethics committee is invited. When they join the conference, Jonathan's parents describe their son's condition accurately. They know he is likely to die, but believe it is their duty to give him every possible chance. "Even if the odds are only 1 in 10,000 or less," his father says, "We must make sure he has every opportunity. He has survived to this point. Only God knows whether he will live or die. Whether in this life or in the next life, I do not want my son to ask me, 'Daddy, why didn't you fight for me?' We cannot agree to stopping any treatment that gives him a chance of survival." One of the physicians asks, "If we exercised authority to withdraw treatment against your wishes, how would you respond?" Jonathan's father replies, "If you do everything for my son and he dies, that is the will of God. But if you do not do everything, then I would blame you for his death."

In the face of this impasse, what should the pediatric ethics committee chairman recommend?²

² Joal Hill, *Clinical Case: Balancing Parental Wishes with Medical Judgment*, 5 VIRTUAL MENTOR 1 (2003).

I. INTRODUCTION: CHILDREN ARE ETHICALLY UNIQUE

In 2003, *Critical Care Medicine* published an article reviewing the 25-year history of do-not-resuscitate (DNR) orders.³ “A DNR order is a written order by an attending physician and precludes resuscitative efforts being undertaken in the event of cardiopulmonary arrest.”⁴ The article observed that the introduction of the DNR order “put appropriate restraint on the universal application of CPR for the dying patient” but concluded that “even today, many of the early concerns remain.”⁵ While there is relatively ample literature on the topic of DNR orders in general, there is comparatively little focus on DNR orders as they pertain both to neonatal patients and to older pediatric patients. This omission is significant because, as I will argue, DNR orders regarding neonatal and pediatric patients are ethically unique. The analysis that would be applicable to considerations of DNR orders as to adult patients would be either inapplicable in whole or in part, or at least incomplete, with regard to neonatal and pediatric patients.⁶

The ethical issues that attend the implementation of DNR orders as to elderly patients are obviously different than those that are relevant with a neonatal or pediatric patient who has just begun their life. Thus, in this paper, I attempt to examine these ethical issues and to ascertain what aspects of ethical discourse as to DNR orders in general might or might not apply to DNR orders for neonatal and pediatric patients. Of course, I am aware that newborn infants and older pediatric patients arguably present as many clinical and ethical differences between them as do pediatric patients and adult patients; so, as the case presentations above suggest, this paper will analyze DNR orders both with respect to neonatal and to older pediatric patients.

³ Jeffrey P. Burns et al., *Do-Not-Resuscitate Orders After 25 Years*, 31 *CRITICAL CARE MED.* 1543, 1548 (2003).

⁴ Mary E. Fallat et al., *Do-Not-Resuscitate Orders for Pediatric Patients Who Require Anesthesia and Surgery*, 114 *PEDIATRICS* 1686, 1686 (2004).

⁵ Burns et al., *supra* note 3, at 1548.

⁶ This is most assuredly not to suggest that the ethics of DNR orders as to adult patients are ethically unproblematic. Quite the contrary, as I hope to demonstrate in Part II, there are a host of ethical problems as to DNR orders in general. Nevertheless, I will attempt to show that what makes DNR status for neonatal and pediatric patients ethically challenging differs, at least in part, from what makes DNR status for adult patients difficult.

II. HISTORY AND ETHICAL ISSUES AS TO DNR ORDERS IN GENERAL

A. A Brief History of DNR Orders: Preservation of Life vs. Prolongation of Suffering

Before turning to analysis of the cases, a general literature review of the ethics of DNR orders in general and then as to neonatal and pediatric patients is warranted. The development of cardiopulmonary resuscitation (CPR) in the early 1960s precipitated the need for DNR orders. As Burns et al. note, CPR “at first seemed miraculous for its effectiveness and simplicity. However, it soon became evident that the routine application of resuscitation efforts to any patient who suffered a cardiopulmonary arrest led to new problems. Far more often than not, CPR transiently restored physiologic stability but prolonged patient suffering.”⁷ Thus, even in the earliest stages of its development, resuscitative measures presented a basic ethical quandary that still underpins much of the controversy over DNR orders today: the potential conflict between prolongation of life itself and the quality of the life preserved. “By the late 1960s articles began appearing in the medical literature describing the agony many terminally ill patients experienced from repeated resuscitations that only prolonged their death.”⁸

DNR orders arose out of the need to address such suffering. In 1974, the American Medical Association noted that “CPR is not indicated in certain situations, such as in cases of terminal irreversible illness where death is not unexpected.”⁹ DNR orders developed out of the general bioethics milieu of the last quarter of the twentieth century, concomitant to “the promotion of patient autonomy. In particular, a broad movement advocated that, in healthcare decisions, the wishes and values of the patient should have priority over those of professionals.”¹⁰

While DNR orders have, by the present day, become a familiar if not regularly encountered phenomenon, Burns et al. do note that “there is less legal certainty for providers regarding DNR orders for incompetent patients.”¹¹ This will have particular relevance for DNR orders for neonatal and pediatric patients, as it is the surrogate—

⁷ Burns et al., *supra* note 3, at 1543.

⁸ *Id.*

⁹ *Id.* at 1543–44.

¹⁰ *Id.* at 1544.

¹¹ *Id.* at 1545.

usually the parent(s)—from whom consent for the entry of a DNR order will be sought.¹²

In terms of actual clinical practice, it seems that DNR orders are often not discussed with patients. In one study of 100 residents surveyed, 71% had been observed discussing DNR orders with patients two or fewer times.¹³ Einav et al. explain that “advance DNR decisions are made only in the minority of cases; either the patient is terminally ill and clearly beyond medical assistance or the competent patient expresses his wish that CPR be withheld.”¹⁴ Accordingly, their study showed only “[16%] of all the physicians participating in the survey estimated that they had discussed DNR approximately 5–10 times during the past year.”¹⁵ Furthermore, in the same study “50% of the respondents admitted that their teams had discussed DNR with a patient or their next of kin less than five times a year.”¹⁶ Einav et al. note that “[t]his finding is consistent with previous studies showing that a DNR decision is . . . avoided despite the fact that not performing CPR may be medically and ethically justifiable.”¹⁷ While the literature shows significant physician reluctance to enter DNR orders in general, I will argue in this paper

¹² However, it should be noted here that CPR is typically considered to be a medical intervention like any other, “and physicians are not ethically bound to seek consent to refrain from a procedure that is not medically indicated.” Burns et al., *supra* note 3, at 1544. This point is actually quite significant, and will be addressed in greater detail below.

¹³ *Id.* at 1545.

¹⁴ S. Einav et al., *Attitudes of Medical Practitioners Towards “Do Not Resuscitate” Orders*, 25 *MED. & L.* 219, 220 (2006). However, part of my project in this essay is to suggest some reasons that even “terminally ill” children “beyond medical assistance” may either have DNR orders not entered at all, or entered well after they would be most effective in preventing suffering (both for the patient and for the parents or surrogates). Moreover, the issue of competency is obviously problematic when dealing with neonatal and pediatric patients, and I will address this as well in *infra* Part III.B. Finally, lurking beneath all of these difficulties is an epistemic problem, viz., attitudes and values of both providers and caregivers will likely influence the clinical decision of when a patient is “clearly beyond medical assistance.” Einav et al. concur, noting that as to DNR orders, “very often[,] ethical and moral issues create a value system that overrides medical considerations.” *Id.* I would suggest that the ethical and moral issues construct and inform the medical considerations rather than “override” them; I do not believe that medical considerations exist in a vacuum independent of value preferences. Miriam Piven Cotler notes that “[c]laims of futility inherently involve questions of values, not questions of medical appropriateness.” *The “Do Not Resuscitate” Order; Clinical and Ethical Rationale and Implications*, 19 *MED. & L.* 623, 626 (2000) (citing Judith Ross, *Judgments of Futility: What Should Ethics Committees Be Thinking About?* 3 *HEC Forum* 4 (1991)). This, of course, hardly diminishes the epistemic problem, which I will also address near the end of this article. See *infra* Part III.B.5.

¹⁵ Einav et al., *supra* note 14, at 224.

¹⁶ *Id.* at 225.

¹⁷ *Id.*

for the existence of some reasons particular to pediatric and neonatal patients that serve to exacerbate the general reluctance as to adult patients.

Finally, Burns et al. note that DNR status varies significantly by specific disease (even where prognosis is similar), gender, race, and particularly, by geographic location.¹⁸ Moreover, “nearly 44% of survivors of in-hospital CPR have a significant decline in functional status.”¹⁹ Insofar as patients are generally unaware of the exact probability of this decline, the fact that such a relatively high percentage of survivors do experience a decline is all the more significant.

B. Principal Ethical Issues as to DNR Orders & the Ethical Dimension of Communication

The reluctance to enter DNR orders is itself fraught with ethical implications insofar as such reluctance may lead to prolongation of suffering even where there exists little expectation of therapeutic benefit. So pronounced is the friction against refraining from initiating CPR that some physicians practice what is known as “slow codes,” where resuscitation is only partially attempted. “Slow codes,” also known as partial, show, light blue, or Hollywood codes, are cardiopulmonary resuscitative efforts that involve a deliberate decision not to attempt aggressively to bring a patient back to life.”²⁰ The inherent deception of slow codes has prompted many commentators to denounce them as ethically impermissible.

The presence of limited codes on teaching hospital autonomy and to prevent physicians from making medicine wards has been criticized as deplorable, dishonest and inconsistent with established ethical principles . . . Slow codes have also been decried as an example of the failure of physicians to face the demanding emotional and intellectual task of talking about futility with patients and families, or to confront their own feelings about their patients’ deaths.²¹

¹⁸ Burns et al., *supra* note 3, at 1546. See generally David S. Zingmond et al., *Regional and Institutional Variation in the Initiation of Early Do-Not-Resuscitate Orders*, 165 ARCHIVES OF INTERNAL MED. 1705 (2005).

¹⁹ Burns et al., *supra* note 3, at 1546.

²⁰ Gail Gazelle, *The Slow Code—Should Anyone Rush to Its Defense?*, 338 N. ENG. J. MED. 467, 467 (1998).

²¹ Jessica H. Muller, *Shades of Blue: The Negotiation of Limited Codes by Medical Residents*, 34 SOC. SCI. MED. 885, 896 (1992) (citing Stuart Younger, *Futility In Context*, 264 J. AM. MED. ASS’N 1276 (1990)); Jessica Muller et al., *Ethical Dilemmas*, ANTHROPOLOGY NEWSL., Dec. 14, 1986; J. Goldenring, *Letter to the Editor*, 300 NEW ENG. J. MED. 1058 (1979); A.L. Evans & B.A. Brody, *The Do-Not-Resuscitate Order in Teaching Hospitals*, 253 J. AM. MED. ASS’N 2236 (1985).

In spite of the fact that slow codes are generally deemed ethically unacceptable, Einav et al., who originally published their study in the journal *Resuscitation* in 2004, reported that “almost two-thirds of the respondents participated in partial codes during [the] past year The current study suggests that practitioners on general medical wards choose to practice deception rather than conversation.”²² Even worse, according to Einav et al., “was the revelation that the practitioners reported doing CPR on patients when no benefit was expected.”²³

In this essay, I will argue that for a variety of reasons, there may be greater reluctance to enter DNR orders for neonatal and pediatric patients as compared to adult patients. Insofar as this argument has merit, there is reason for believing that the imperative that prompts physicians to initiate slow codes for adult patients may have even greater effect when neonatal and pediatric patients are present. My research does not reveal any published studies on the frequency of slow codes for either neonatal or pediatric patients. Nevertheless, the prevalence of such slow codes among adult patients is all the more disturbing for what it suggests might happen—or might already be happening—to neonatal and pediatric patients.

Aside from the value conflict of preservation-of-life versus prolongation-of-suffering, Burns et al. identify four additional ethical issues as to the entry of DNR orders. First, the existence of ambiguity as to what constitutes CPR is a serious problem. This is because “any general anesthetic involves the deliberate depression of vital systems, followed by their resuscitation. Separating anesthesia from resuscitation is therefore difficult and somewhat artificial.”²⁴ Even so, the American Society of Anesthesiologists has expressly rejected the notion that DNR orders should be automatically rescinded before procedures involving the use of anesthesia, because this practice “may not sufficiently address a patient’s rights to self-determination in a responsible and ethical manner.”²⁵

Second, there remains “[s]ubstantial variability and inconsistencies . . . as to which patients are asked about their wishes involving CPR (and have these wishes recorded).”²⁶ Third, DNR orders are frequently and erroneously interpreted by patients and families as

²² Einav et al., *supra* note 14, at 226–27.

²³ *Id.* at 227.

²⁴ Burns et al., *supra* note 3, at 1547; *see also* Fallat et al., *supra* note 4.

²⁵ Burns et al., *supra* note 3, at 1547.

²⁶ *Id.* at 1548.

limitations on most, if not all non-resuscitative forms of treatment.²⁷ Whether this is a true ethical dilemma or a simple problem of communication will be addressed in detail below, but this does demonstrate a recurring feature of situations where DNR status is at issue: the ethical dimension of communication. The argument is that effective communication can obviate or even potentially eliminate serious ethical problems.

Finally, “[d]isagreement persists as to whether there are circumstances in which physicians may unilaterally determine that CPR is not indicated.”²⁸ The difficulties with DNR orders prompted one clinical ethicist to ruefully observe that “[r]ather than increasing the likelihood of actions consistent with respect and dignity for the patient, confusion and reluctance surrounding the entire DNR process is an ethical minefield.”²⁹

These problems of communication are not limited to end-of-life care for adult patients. One study of end-of-life care of pediatric oncology patients “identified physician communication as a problem area . . . researchers who have studied the psychosocial concerns of bereaved parents have reported that families find physician communications vague and confusing, which can lead to anger or a feeling of responsibility for the death of one’s child.”³⁰ While difficulties in communicating about end-of-life care cross boundaries between adult and child, there remain significant ethical issues that attend DNR orders for neonatal and pediatric patients that are unique. I now turn to a discussion of these differences.

III. ETHICAL ISSUES AS TO DNR ORDERS FOR NEONATAL AND PEDIATRIC PATIENTS

Having completed this exceedingly brief survey of the development of DNR orders and some of the typical ethical issues that

²⁷ *Id.*

²⁸ *Id.* However, as mentioned above, CPR is properly considered a medical intervention, the application of which is ultimately left to the clinical judgment of the physician. This does not mean that there can exist no controversy over the physician’s judgment, of course, but simply that the privilege—and the responsibility—of deciding whether to initiate CPR should, in the end, reside with the treating physician. I will address this point in greater detail in Part III.B.4–5.

²⁹ Cotler, *supra* note 14, at 631.

³⁰ Joanne M. Hilden et al., *Attitudes and Practices Among Pediatric Oncologists Regarding End-of-Life Care: Results of the 1998 American Society of Clinical Oncology Survey*, 19 J. CLINICAL ONCOLOGY 205, 209 (2001).

attend their entry, I now move on to examine some of the ethical issues that apply specifically to neonatal and pediatric patients.

A. The Great Reluctance to Enter a DNR Order for Pediatric Patients

The first and arguably most important point in understanding the ethical issues that attend pediatric and neonatal DNR orders has already been mentioned: children are ethically unique when it comes to end-of-life issues. Postovsky et al. note in two different articles that “[t]he last days, hours, and minutes of the child’s life will most probably remain forever in the parents’ minds, and how their child dies is of critical importance for the parents’ further lives.”³¹ Because children are viewed as just beginning their lives, one would likely infer that parents, as surrogate decision-makers, would display greater reluctance to agree to a DNR order than surrogates of older patients, or perhaps even older patients themselves.

Singh et al. confirm this, observing that “[m]ost of our patients do not want to stop intensive care if there is a chance of survival, and most are willing to continue medical intervention even in the face of a high probabilistic prediction of morbidity.”³² Similarly, clinicians might be reluctant to broach the topic of DNR orders with parents for the same reasons parents might be unwilling to agree to their entry. In turn, physician unwillingness to discuss DNR orders with parents may itself constitute an ethical issue insofar as the literature overwhelmingly observes that DNR orders are “discussed with parents all too seldom and too late in clinical practice.”³³

As Garros et al. conclude, “[t]alking to families or surrogates about [end-of-life] issues is very challenging to most physicians. Only 41% of the patients in the . . . study engaged in discussion with their physicians about CPR, and in 80% of the cases, physicians misunderstood the patient’s preferences.”³⁴ Hilden et al. note that “both

³¹ Sergey Postovsky et al., *Care of a Child Dying of Cancer: The Role of the Palliative Care Team in Pediatric Oncology*, 21 PEDIATRIC HEMATOLOGY & ONCOLOGY 67, 67 (2004); Sergey Postovsky et al., “Do Not Resuscitate” Orders Among Children with Solid Tumors at the End of Life, 21 PEDIATRIC HEMATOLOGY & ONCOLOGY 661, 661 (2004) [hereinafter Postovsky, *Do Not Resuscitate*].

³² Jaideep Singh, et al., *End-of-life After Birth: Death and Dying in a Neonatal Intensive Care Unit*, 114 PEDIATRICS 1624 (2004).

³³ Postovsky, *Do Not Resuscitate*, *supra* note 31, at 665.

³⁴ Daniel Garros, et al., *Circumstances Surrounding End of Life in a Pediatric Intensive Care Unit*, 112 PEDIATRICS 371, 376 (2003).

physicians and parents tend to use all available therapy options, no matter what the condition of the child.”³⁵

Postovsky et al. contend that the positive effects of DNR orders may be diminished or even eliminated by DNR orders implemented only a short time before the patient dies.³⁶ “Ordering DNR during the last 24 h[ours] of the patient’s life is not timely as this short span of time does not provide parents and other relatives with a sufficient amount of time to fully and optimally prepare for the child’s death.”³⁷ One cannot overestimate the emotional and psychological functions DNR orders may serve for parents facing the death of their child.³⁸

Moreover, Postovsky et al. observe the significant “discrepancy between parents’ understanding of the child’s ultimate prognosis and that of his/her treating physician.”³⁹ In one study, parents tended to realize the lack of any realistic chance of cure almost 100 days later than did physicians.⁴⁰ Postovsky et al. suggest that one of the reasons for such a divergence may be that “[p]arents may see such a decision as betraying their child.”⁴¹ As such, it is not surprising that disagreement on end-of-life decisions between parents and physicians “is most likely to occur in cases of severely ill infants who are expected to survive with very poor quality of life.”⁴² The literature supports the view that there is great reluctance to enter DNR orders on the part of all actors involved in end-of-life decision-making pertaining to neonatal and pediatric patients.

B. ADDITIONAL REASONS NEONATAL AND PEDIATRIC PATIENTS ARE ETHICALLY UNIQUE

Aside from the social view of children that inform end-of-life decision-making for pediatric patients and their surrogates, a recent article illuminates several clinical and economic reasons why pediatric patients are ethically unique.

³⁵ Hilden et al., *supra* note 30, at 209–10.

³⁶ See Postovsky, *Do Not Resuscitate*, *supra* note 31, at 665.

³⁷ *Id.* at 667.

³⁸ *Id.* at 664–65.

³⁹ *Id.* at 666.

⁴⁰ *Id.*

⁴¹ Postovsky, *Do Not Resuscitate*, *supra* note 31, at 666.

⁴² Agnes van der Heide et al., *The Role of Parents in End-of-Life Decisions in Neonatology: Physicians’ Views and Practices*, 101 *PEDIATRICS* 413, 413 (1998).

Advances in neonatal medicine have resulted in the survival of babies previously considered non-viable. However, the morality of providing life sustaining treatment (LST) . . . has been questioned, as survival may impose considerable burdens of morbidity and neurodevelopmental impairment on babies, careers, and society. All neonatal teams therefore regularly face the need to make decisions to withhold or withdraw LST or to issue do not resuscitate (DNR) orders.⁴³

There are several ethical issues worth unpacking here. First, there is the aforementioned concern that failure to properly implement DNR orders may result in prolongation of suffering for the sake of a medically futile intervention.⁴⁴ Postovsky et al. argue that DNR orders are needed for pediatric cancer patients precisely because they may help avoid such interventions, and because they “allow concentration on the management of suffering and preservation of the patient’s dignity.”⁴⁵ “[T]he child’s welfare is best served by not having a poor quality of life unnecessarily prolonged and [by] not having to endure ineffective therapy.”⁴⁶

As to the reluctance to enter DNR orders for adult patients, Einav et al. point out a disturbingly high prevalence of the wishes of a competent patient being overridden by physician preference: “[i]t is unfortunate that patients’ preferences are overridden by overzealous medical practice and that patients are often subjected to medical interventions and investigations up to the time of death.”⁴⁷ Ethical analysis of DNR orders for neonatal and pediatric patients is necessarily different because of such patients’ general lack of competence.⁴⁸ However, the differences between how physicians view children and how they view adults renders it all the more likely, as Postovsky et al. and Singh et al. confirm,⁴⁹ that neonatal and pediatric patients are at even greater risk of being “subjected to medical interventions up to the time of death.”⁵⁰

An important, related notion of DNR orders for pediatric patients is that “a DNR order might be the first step in a process that is

⁴³ R. Roy et al., *Decision Making and Modes of Death in a Tertiary Neonatal Unit*, 89 ARCHIVES OF DISEASE CHILD FETAL NEONATAL ED. F527 (2004).

⁴⁴ Postovsky, *Do Not Resuscitate*, *supra* note 31, at 665.

⁴⁵ *Id.*

⁴⁶ Fallat et al., *supra* note 4, at 1687.

⁴⁷ Einav et al., *supra* note 14, at 226.

⁴⁸ See Allison Mantz, *Do Not Resuscitate Decision-Making: Ohio’s Do Not Resuscitate Law Should be Amended to Include a Mature Minor’s Right to Initiate a DNR Order*, 17 J.L. & HEALTH 359, 365 (2002–2003).

⁴⁹ See *supra* notes 31–42 and accompanying text.

⁵⁰ Einav et al., *supra* note 14, at 226.

subject to frequent reevaluations of its goals; [i]t seems to be easier for the families to agree initially with limitation rather than active withdrawal of [life-sustaining treatment].”⁵¹ Though ethicists have argued for some time that there is no substantive moral difference between a decision not to initiate life-sustaining treatment (which includes but is not limited to CPR) and a decision to withdraw such treatment, clinical practice has not tracked that perspective. Numerous studies demonstrate much greater reluctance to withdraw LST than to refrain from administering it in the first place.⁵²

Thus, not only are DNR orders of independent ethical import, they may be of heightened significance because they facilitate the “active withdrawal of LST.”⁵³ DNR orders are important partly because they may make it easier for families to commence active withdrawal of LST, which itself may ameliorate the possibility of prolonging a pediatric patient’s suffering. Of course, this benefit of DNR orders renders their usage all the more important. As Garros et al. note, “waiting and watching is no longer a good option.”⁵⁴

Moreover, the possible time span of suffering after resuscitation is potentially far longer for neonatal and pediatric patients than for adult patients.⁵⁵ The effects of possible impairments on patients, caregivers, and social resources tapped to subsidize and provide care are therefore quantitatively, if not qualitatively different from those that attend adult patients who survive resuscitative measures. The social and emotional costs of resuscitating infants and children—especially where the evidence suggests that the risk of material impairment and dysfunction is relatively high—exert tremendous pressures on all moral agents involved in end-of-life decision-making for pediatric patients.⁵⁶

1. *Ethical Issues Relating to Inability to Consent*

Serious ethical issues arise because many pediatric patients are not competent to consent to medical treatment, and therefore require surrogate consent. However, age of consent or assent can be nebulous with regard to pediatric patients. “Older children and ado-

⁵¹ Garros et al., *supra* note 34, at 376.

⁵² *See id.*

⁵³ *Id.*

⁵⁴ *Id.*

⁵⁵ *See generally* Roy et al., *supra* note 43, at F527.

⁵⁶ Of course, this assumes a certain value priority afforded to quality of life. A committed vitalist might well disagree on the extent of the pressure produced by the risk of material dysfunction that attends CPR.

lescents should be included in the decision-making process (patient assent) when their neurologic status, development, and level of maturity allow.”⁵⁷ The rub, of course, is in assessing whether a specific patient manifests such characteristics as to “allow” for consent.⁵⁸

The fact that neonatal patients are unquestionably not competent to consent or assent to any treatment or lack thereof requires that surrogate decision-makers act in the best interests of the infant. When the surrogate is a parent, psychological and emotional factors may make it difficult to perceive the best interests of the infant among the range of medical options. This, in turn, may raise the specter of prolonged suffering for the neonatal patient. However, one commentator suggests that even if parents choose to proceed with resuscitation despite the apparent futility of such a mode of action, they should not and cannot be blamed for this. According to this line of reasoning, it is more a failure of the palliative team in not coming to terms with the parents when such a possibility was contemplated, rather than the parents who are at fault.⁵⁹

Though this perspective may be somewhat controversial, it nevertheless reflects again the ethical dimension of communication. If it is the care team’s responsibility to explain that prolongation of suffering is likely to ensue, and CPR is not in the best interests of the child, the communication of that information itself takes on ethical significance.

In legal terms, the fact that neonatal patients have *never* been competent to consent demonstrates the total inapplicability of what is termed the substituted judgment standard of surrogate decision-making.

2. ‘Best Interests’ vs. ‘Substituted Judgment’ Standard

Some American jurisdictions have adopted the substituted judgment standard as a test for assessing the merits of surrogate decision-making for incompetent patients.⁶⁰ The substituted judgment standard focuses attention on whether the surrogate has substituted the incompetent patient’s judgment for the surrogate’s judgment, that is, whether the surrogate’s decision is what the pa-

⁵⁷ Fallat et al., *supra* note 4, at 1687.

⁵⁸ This is obviously a separate issue onto itself, and is thereby beyond the scope of this paper.

⁵⁹ Postovsky, *Care of a Dying Child*, *supra* note 31, at 69.

⁶⁰ Lynn E. Lebit, *Compelled Medical Procedures Involving Minors and Incompetents and Misapplication of the Substituted Judgments Standard*, 7 J.L. & HEALTH 107, 125–26 (1992); D. Don Welch, *Walking In Their Shoes: Paying Respect to Incompetent Patients*, 42 VAND. L. REV. 1617, 1637–38 (1989).

tient would have decided were the patient competent to make the decision.⁶¹

Note that this is a different legal (not to mention ethical) standard than the best interests standard, which weighs whether the surrogate's decision is in the best interests of the patient.⁶² Under the substituted judgment standard, the surrogate is literally a proxy for the patient.⁶³ The surrogate is supposed to make the same end-of-life decision that the patient himself or herself would have made. This is certainly not equivalent to a best interests standard, because sometimes a competent patient may indeed make a medical decision that is arguably not in his or her best interests. A strict substituted judgment standard does not allow for a surrogate decision that evidence shows is different from what the patient would have decided, even if the evidence demonstrates that the surrogate's decision is in the best interests of the patient.⁶⁴

One Dutch study concluded that it may not make sense to discuss patient autonomy with regard to neonatal patients facing end-of-life issues, finding that "parents are the proxies to decide for their infant who is unable to judge and make decisions about its own life."⁶⁵ The study states that parents essentially act as proxies for neonatal patients as to end-of-life decision-making, but it is legitimate to question whether the substituted judgment standard even makes sense as to neonatal patients.⁶⁶ After all, where development has barely begun, or, as is often the case with neurologically impaired infants, where meaningful cognitive development is clinically dubious, in what sense can the patient be said to have *ever* possessed a capacity for judgment? The premise of the substituted judgment standard is that the incompetent patient was once competent to make treatment decisions. In the case of a neonatal patient born with significant impairments, this premise is questionable.

Thus, the applicability of the substituted judgment standard to neonatal patients is dubious. A best interests standard seems better suited.⁶⁷ This in itself points out a conceptual, legal, and ethical dif-

⁶¹ Lebit, *supra* note 60, at 125–26.

⁶² *Id.*

⁶³ *Id.*

⁶⁴ *Id.* at 110.

⁶⁵ van der Heide et al., *supra* note 42, at 417.

⁶⁶ *Id.*

⁶⁷ This, of course, is not to deny the significant problems that attend the use of a best interests analysis as to neonatal and pediatric patients facing end-of-life scenarios. Sadath Sayeed articulates some of these problems in his recent article, *The Marginally Viable New-*

ference between older pediatric patients and neonatal patients. The fact that older pediatric patients may possess some form of judgment, even if they are not competent to consent to end-of-life decisions, may at least allow for, if not commend, the application of a substituted judgment assessment, whereas such assessment seems nonsensical for neonatal patients.

Norman Cantor articulated this point in detail in his recent article, *The Bane of Surrogate Decision-Making: Defining the Best Interests of Never-Competent Persons*.⁶⁸ He notes that “[p]rofoundly disabled persons, by definition, have never had the capacity for autonomy,”⁶⁹ and that, therefore, “the bulk of commentators and courts have rejected application of a substituted judgment standard—a standard seeking to replicate the patient’s own likely decision—in the context of a never-competent person.”⁷⁰

Cantor specifically addresses profoundly disabled infants and children in this context, and notes that “[t]he difficulty of surrogate decision-making is compounded in the case of newborns whose prognoses are ultimately dismal, but whose precise levels of pain and cognitive dysfunction cannot yet be fixed.”⁷¹ He also explains that broad deference to parental decision-making regarding the care and custody of the child is enshrined in American law.⁷² This deference acts as a kind of jurisprudential mirror for the extreme reluctance to address DNR issues with parents of neonatal and pediatric patients. Apparently, the law, much like providers, generally grants broad deference to parental decision-making for neonatal and pediatric patients, such that “parents generally are allowed flexibility in making medical choices for their offspring, even if the choices deviate from the child’s best interests.”⁷³

born: *Legal Challenges, Conceptual Inadequacies, and Reasonableness*, 34 J. L. MED. & ETHICS 600, 605–607 (2006). My essay should not be taken as a committed defense of the best interests standard. I believe, as does Sayeed, that such “analysis is capable of doing . . . work in some cases,” though I also agree with him that “it struggles when pushed to analytic limits.” *Id.* at 605. My purpose in this section is simply to suggest why a substituted judgment standard makes little sense for never-competent patients, and thus to articulate a potential difference between neonatal or even older pediatric patients and adult patients who were once competent.

⁶⁸ 26 J. LEGAL MED. 155 (2005).

⁶⁹ *Id.* at 158.

⁷⁰ *Id.*

⁷¹ *Id.* at 164. This also speaks to the epistemic difficulty mentioned in *supra* note 14, and which will be addressed in *infra* Part III.B.5.

⁷² Cantor, *supra* note 68, at 183–88.

⁷³ *Id.* at 188.

Thus, while the application of a substituted judgment standard would seem to make little sense, most jurisdictions grant substantial deference to parental decision-making. In such jurisdictions, decisions made that arguably may not be in the best interests of the child will nevertheless be legally acceptable.⁷⁴ The law, therefore, underscores a point advanced in this essay, that there is great reluctance to differ with parents as to end-of-life decisions regarding their children.⁷⁵ I argue in this essay that there may exist an ethical duty to dissent from such decisions. Cantor agrees, and concludes that

[n]ever-competent persons, as possessors of full moral status, are entitled to be treated with dignity. This normally means that a surrogate decision-maker will maximally preserve the life of a ward. Sometimes, though, respect for the intrinsic human dignity of a fatally stricken ward dictates that the ward be allowed to die. A permanently unconscious person offers an example, as does an infant with multiple deficits whose short life will be pervaded by intrusive medical interventions. In these rare instances, the deterioration or debilitation of a human being is so extreme that further medical intervention would be inhumane. This is so for some never-competent persons, just as it is for some formerly competent persons.⁷⁶

This is, in my opinion, exactly right, and insofar as DNR orders are an important implement for furthering these ethical considerations, communication about their usage is all the more imperative.

While the law reflects the latitude given to parental decision-making in end-of-life scenarios, it also recognizes a difference in the kind of competency that an older child may possess: the mature minor doctrine. Several states have actually enacted statutes that codify a mature minor's competence to consent to DNR orders.

⁷⁴ *Id.*

⁷⁵ Again, this is not to suggest that policies of broad deference are ill-advised. Quite the contrary, such policies exist for sound reasons and are often, perhaps even usually, sound practice. MacDonald et al. recommend that "[p]arental choice regarding management of the delivery and subsequent care of the infant [be] respected within the limits of medical feasibility and appropriateness." Hugh MacDonald & Committee on Fetus and Newborn, *Perinatal Care at the Threshold of Viability*, 110 *PEDIATRICS* 1024, 1027 (2002). Such deference, however, cannot be reflexive, and must be examined on a case-by-case basis to determine if the decision as to DNR status comports with the care team's concept as to the patient's best interests. While the law may permit parental decisions that are not in the best interests of the child, it does not follow that the provider must always refrain from entering DNR orders if he or she has a good faith belief that LST is not warranted for a particular patient. Indeed, the argument in this essay is that a provider has an ethical obligation to do so.

⁷⁶ Cantor, *supra* note 68, at 205.

3. *Consent Under the Mature Minor Doctrine*

It is self-evident that the ability of minors to consent is not uniform for all minors. Though minors are generally incompetent to make medical decisions, the mature minor doctrine represents an exception to that rule.⁷⁷ Both West Virginia⁷⁸ and New York⁷⁹ have enacted DNR statutes that specifically provide that minors who are judged competent must consent to the entry of a DNR order for it to be valid.⁸⁰

The West Virginia statute is of particular interest here. It provides, in pertinent part, that

[i]f the minor is between the ages of sixteen and eighteen and, in the opinion of the attending physician, the minor is of sufficient maturity to understand the nature and effect of a do-not-resuscitate order, then no such order shall be valid without the consent of such minor. In the event of a conflict between the wishes of the parents or guardians and the wishes of the mature minor, the wishes of the mature minor shall prevail. For purposes of this section, no minor less than sixteen years of age shall be considered mature.⁸¹

The Supreme Court of West Virginia applied the provision in *Belcher v. Charleston Area Med. Ctr.*, and ruled that the defendant physician had failed to properly obtain the seventeen-year-old patient's consent to the entry of a DNR order because the patient qualified under the mature minor exception.⁸²

Though the case did not present a scenario in which the provider and the parents disagreed, the Court did opine on what should happen where the parents or surrogates disagree on whether a DNR order should be entered: "Where there is a conflict between the intentions of one or both parents and the minor, the physician's good faith assessment of the minor's maturity level would immunize him or her from liability for the failure to obtain parental consent."⁸³ In other words, the physician is granted authority under the law, so long as he or she acts in good faith, to act contrary to the parents' wishes with regard to their child's DNR status. This ruling is significant insofar as it embodies what I deem to be an, if not the, ethically important standard: the physician's responsibility is to the patient first and foremost. While intricate issues of competency and

⁷⁷ Mantz, *supra* note 48, at 370.

⁷⁸ W. VA. CODE ANN. § 16-30C-6(c) (LexisNexis Supp. 2006).

⁷⁹ N.Y. PUB. HEALTH LAW § 2967 (McKinney Supp. 2006).

⁸⁰ Mantz, *supra* note 48, at 374-76.

⁸¹ W. VA. CODE ANN. § 16-30C-6(c) (LexisNexis Supp. 2006).

⁸² 422 S.E.2d 827, 830, 836-37 (W. Va. 1992).

⁸³ *Id.* at 838.

consent obviously inform that responsibility such that parents and surrogates become hugely important parts of the decision-making process, these issues do not signify the lack of *any* kind of dyadic ethical relationship between physician and patient.

The *Belcher* Court's ruling on cases of parental conflict with the wishes of the older pediatric patient demonstrates the importance of exercising independent judgment on the entry of a DNR order.⁸⁴ To be sure, the Court narrowly framed the physician's authority in terms of whether the patient qualifies as a mature minor such that it is the patient whose consent is needed to enter a DNR order,⁸⁵ but, for my purposes, the key lies in understanding that the physician's ethical obligations lie first and foremost to the patient, not to the parents or surrogates. Even where pediatric or neonatal patients obviously do not qualify under the mature minor doctrine, or in jurisdictions where the doctrine is inapplicable, the provider may still have an ethical obligation to dissent from the parent or surrogate's wishes as to DNR status.

4. *The Ethical Obligation to Disagree with Surrogate Decision-Making*

Perhaps the principal ethical difficulty for clinicians caring for neonatal patients that face end-of-life scenarios is the specter of dissent from a parent's decision as to DNR status. One study of extremely premature infants found that physicians virtually always deferred to the wishes of the parents on resuscitation: "Whereas treatment was invariably withheld when parents desired comfort care only, resuscitation was provided in 50% of the cases in which physicians preferred comfort care only."⁸⁶

Physicians who reflexively comply with the parents' end-of-life decisions may be violating ethical responsibilities owed to the neonatal patient. "Acting in accordance with the principle of respecting the opinion of parents about which course of action is in the best interest of their child may occasionally collide with the medical motive of avoiding any pointless suffering of the infant."⁸⁷

The decision of whether to enter a DNR order is a question of whether to medically intervene in case of cardiac arrest and, as

⁸⁴ *Id.*

⁸⁵ *Id.*

⁸⁶ Mia Doron et al., *Delivery Room Resuscitation Decisions for Extremely Premature Infants*, 102 *PEDIATRICS* 575 (1998).

⁸⁷ van der Heide et al., *supra* note 42, at 418.

such, is ultimately within the ambit of the physician's clinical judgment (even acknowledging that the clinical judgment is necessarily and inevitably informed by value preferences and normative considerations). Einav et al. concur, noting that "[u]ltimately[] . . . the decision regarding the clinical virtue of attempting resuscitation and the quality of the CPR lies upon the shoulders of the treating physician on location."⁸⁸ A physician is under no ethical or legal obligation to comply with the surrogate's demands regarding the DNR order. Of course, this is not to suggest the absence of some compelling prudential reasons why the physician or the care team might comply with the parent's choices. The criticism here is of reflexive compliance, of compliance merely because of the *ipse dixit* of the parents.

To that end, New York's DNR law, for example, codifies the notion that the decision to enter a DNR order, while obviously constructed on and informed by ethical mores, remains a clinical decision of the physicians:⁸⁹ "New York's DNR law authorizes unilateral physician determinations to issue a DNR order based on medical futility when the patient is incompetent and has no known surrogates to make decisions."⁹⁰

There ought to be space for physicians to exercise their professional discretion, to make recommendations based on their best judgment, and, to act on those recommendations where appropriate, such as where surrogate preferences as to DNR status seem to conflict with the physician's best judgment of what interventions are or are not merited for a neonatal or pediatric patient. To deny this would be to endorse an abdication of the very professional role that informs the patient or surrogate's decision to seek treatment. Kevin Gibson argues that "[s]imply deciding . . . to elect surgery

⁸⁸ Einav et al., *supra* note 14, at 228.

⁸⁹ Edward F. McCardle, *New York's Do-Not-Resuscitate Law: Groundbreaking Protection of Patient Autonomy or a Physician's Right to Make Medical Futility Determinations?* 6 DEPAUL J. HEALTH CARE L. 55, 63 (2002). Though I have already made the point in this paper, it is worth re-emphasizing: my use of the term "clinical judgment" is not intended as an antipode to the terms "value judgment" or "ethical judgment." The physician's clinical judgment reflects value preferences and ethical mores. See *supra* note 14. However, it does not follow from the mere fact that clinical judgments incorporate ethical mores that patients or surrogates themselves ought to have sole discretion to enter DNR orders. There is no doubt that the best kinds of end-of-life decision-making involve dialogue between providers and caregivers, see Cotler, *supra* note 14, at 627, but the situation addressed *ex hypothesi* in this paper is a conflict between providers and surrogates. This is because where there is no disagreement among the care team, the patient, caregivers, and/or surrogates as to whether to enter a DNR order, no ethical dilemma exists.

⁹⁰ McCardle, *supra* note 89, at 63.

instead of drug therapy is a vacuous choice without the assent and collaboration of others who have the power to help realize those decisions.”⁹¹ While I do not necessarily agree that such a choice would be vacuous, I do agree with Gibson’s implicit point that the provider’s perspective is inherently valuable to the practice of patient or surrogate decision-making. The fact that the surrogate may well disagree with the provider’s judgment is, in and of itself, insufficient justification for simply acquiescing, in all circumstances, to the surrogate’s preferences as to DNR status for pediatric or neonatal patients.

Of course, this is not to argue for a physician’s *carte blanche* authority, nor to deny the possibility of abuse of the physician’s power. The tone in which the provider communicates his/her judgment and professional recommendation is obviously significant as well. The argument that a provider ought to share recommendations even where the provider differs with patients or surrogates ought not imply support for heavy-handed, abusive exercises of power.

The concept of “active listening” may suggest one possible means of ameliorating such abusive practices. Active listening “focuses on attending to patients’ clues, i.e., utterances and/or behaviors that are not explicit but may have special meaning and suggest unshared ideas, concerns, and expectations. Skill in active listening is required to recognize and explore these clues.”⁹² Gregg Bloche notes that active listening techniques may be of particular importance when a patient can “no longer formulate preferences,”⁹³ and he endorses practices born of mediation in end-of-life decision-making: “Good mediation technique can help to clarify misunderstandings, soften anger, and ease irrational distrust.”⁹⁴

The idea, then, is to make recommendations that resonate with the patient and/or the surrogate, which seems to underscore the

⁹¹ Kevin Gibson, *Mediation in the Medical Field: Is Neutral Intervention Possible?* 29 HASTINGS CTR. REP. 6, 8 (1999).

⁹² Forrest Lang et al., *Clues to Patients’ Explanations and Concerns About Their Illnesses*, 9 ARCH. FAM. MED. 222, 222 (2000). This article address active listening in the context of patients, not surrogates. There seems, however, little basis to argue that such techniques are less desirable or useful when communication with surrogates is at issue. Indeed, Bloche argues that the need for active listening techniques may be more important where the patient is unable to communicate their preferences. See *infra* note 83 and accompanying text.

⁹³ Gregg Bloche, *Managing Conflict at the End of Life*, 352 N. ENG. J. MED. 2371, 2372–73 (2005).

⁹⁴ *Id.* at 2373. See generally NANCY DUBLER & CAROL LEIBMAN, *BIOETHICS MEDIATION* (2004).

ethical significance of communication.⁹⁵ Bloche notes that “[a] large literature suggests that solutions crafted by the parties to a conflict come with a sense of shared ownership that dampens discord.”⁹⁶ It is difficult to see how such shared ownership of decision-making is realizable where the provider simply acquiesces to whatever decision the surrogate makes. Moreover, shared partnership does not imply an equal “division of responsibility.”⁹⁷ The provider has a responsibility to exercise their judgment, share that judgment with the patient and/or the surrogate, and, in certain cases, even to rely on that judgment as a basis for differing with the surrogate’s judgment regarding DNR status of neonatal or pediatric patients.

Naturally, shared ownership is an aspiration that may not be realized in such cases, but the ethical imperative is the same even where a shared decision is unattainable: the provider’s judgment is a vital part of the medical decision-making calculus. This is no less valid where the exercise of that judgment suggests to the provider that a proposed intervention is unwarranted and perhaps unethical. In this case, silencing that judgment diminishes the value and import of the notion of collaboration in decision-making. Such silence, of course, may also violate ethical duties that are owed to the patient. This is not to deny the existence of ethical duties owed to the surrogate or family, but merely to argue that these duties are not equivalent.

5. Case Analysis

It is this analysis that is crucial regarding the cases described at the beginning of this paper. As to Angela’s case, an infant born at 27 weeks of gestation, currently registering oxygen saturation levels in the thirties, forties, and fifties, is either unlikely to survive or will survive with pronounced, even severe, impairments. It seems legitimate in this circumstance for the care team to approach Angela’s mother and grandmother, and to communicate the likelihood of

⁹⁵ One way of conceiving of such practices is via the “interpretive model” of the physician-patient relationship, which emphasizes the physician’s role as counselor “whose responsibility it is to elucidate the patient’s values and to help the patient select the interventions that realize these values.” Deborah Cook, *Patient Autonomy Versus Parentalism* [sic], 29 CRIT. CARE. MED. N24 (2001) (citing Ezekiel J. Emanuel & Linda J. Emanuel, *Four Models of the Physician–Patient Relationship*, 267 JAMA 2221 (1992)).

⁹⁶ Bloche, *supra* note 93, at 2372.

⁹⁷ Carol Levine & Connie Zuckerman, *The Trouble with Families: Toward an Ethic of Accommodation*, 130 ANN. INT. MED. 148, 151 (1999).

permanent, severe disability and/or significant suffering that would attend the implementation of resuscitative measures.

Of course, another realistic feature of both Angela's and Jonathan Roland's cases is the fact that the clinical prognosis itself is unsettled. To be sure, where the care team simply is not certain whether resuscitative measures would be futile due to the uncertain nature of the patient's prognosis, entering a DNR order in the face of parental opposition may neither be ethically optimal nor the most prudential course of action. Clinical uncertainty in these cases is, in fact, *de rigueur*, which means, of course, that the decision of whether to undertake resuscitation is almost never obvious when dealing with marginally viable neonatal patients. Sayeed concludes that

[m]ost, if not all neonatal practitioners recognize a basic flaw in any approach that attempts to draw a sharp line separating those newborns ex ante well-suited for resuscitation versus those who are not. No set of inclusion/exclusion criteria are perfect, but unparalleled uncertainty about outcomes often prohibits pursuit of a singularly rational therapeutic or palliative course of care at the time of delivery, and thus a degree of flexibility in management practice and an honest assessment of our limited capabilities and society's limited support for debilitated survivors seem reasonable places to start⁹⁸

Thoughtful flexibility is, I would argue, the proper antithesis to a reflexive obeisance to parental or surrogate decision-making as to DNR status, so long as such flexibility is accompanied by a willingness to (carefully, respectfully, and appropriately) raise the question of DNR status early enough to be maximally helpful.

Jonathan Roland's case (Case #2) places the ethical quandaries in perhaps starker contrast, with the child's father essentially informing the Ethics Committee that a decision to withhold resuscitative measures would be tantamount to causing his death in the father's eyes. Such a scenario illustrates the tremendous pressures on both the care team and on the parents when faced with the prospect of a child apparently on a dying trajectory. It is not difficult to see how and why Jonathan's treating physician might be loath to change Jonathan's DNR status upon hearing the pronouncement of the father, never mind to broach the subject of DNR status with parents of future pediatric patients.

Nevertheless, where the physician owes ethical obligations to the pediatric patient, and where the physician is convinced that CPR would simply prolong the child's suffering and is not medically warranted (*i.e.*, is futile), the physician's ethical responsibility

⁹⁸ Sayeed, *supra* note 67, at 609.

would seemingly be to communicate that information as well as is possible and to make the appropriate clinical decision. Note that I am not ignoring the fact that decisions of medical futility are absolutely normative, value-laden concretions. Sayeed notes that “[e]xcept in the clearest of cases, utilization of the concept [of futility] involves a moral leap, that is deciding what should be done instead of what can be done—which necessarily entails a normative judgment about the value of certain on-going manifestations of human life.”⁹⁹

Sayeed argues that the proper legal response to the necessarily normative consideration of futility is to ensure a “fair procedural framework—one that, at a minimum, guarantees families an opportunity to seek alternative care, when they disagree with physicians’ assessments and recommendations in particular cases.”¹⁰⁰ This strikes me as an entirely measured and appropriate recommendation. Moreover, I wish to make clear that my insistence that physicians exercise their own independent judgment on the merits of parental reluctance to enter a DNR order should not be taken as a commitment to the medicalizing or the inherent privileging of medical determinations in excruciating end-of-life decision-making for neonatal or pediatric patients. I am not advocating the reflexive imposition of physician values and attitudes as to DNR status. Indeed, my critique is of reflexivity *per se*.

Nevertheless, the need for physicians and the care team to exercise their own independent judgment—both clinical and ethical—of whether a DNR order is warranted is all the more important given the inherent friction against entering DNR orders with regards to pediatric and neonatal patients. Van der Heide et al. point out that “the preservation of life when possible seems to be the predominant principle in neonatology, which may be abandoned only

⁹⁹ *Id.* at 604.

¹⁰⁰ *Id.* Sayeed cites with approval a recent case study from Texas implicating the procedural scheme codified in the Texas Advance Directives Act. *Id.* (citing R.L. Fine et al., *Medical Futility in the Neonatal Intensive Care Unit: Hope for a Resolution*, 116 PEDIATRICS 1219 (2005)). However, given the recent controversy about the propriety of that scheme, I am hesitant to endorse it unreservedly. See Ronald L. Scott, *Texas Legislature Should Address Procedural Inadequacies in Advance Directives Act*, [http://www.law.uh.edu/healthlaw/perspectives/2006/\(RS\)Spiro%20Nikolouzos%201.pdf](http://www.law.uh.edu/healthlaw/perspectives/2006/(RS)Spiro%20Nikolouzos%201.pdf) (last visited Oct. 8, 2006) (stating that the Texas Legislature seems primed to reexamine the framework of the Act in the upcoming 80th Regular Session). I do agree, however, with Sayeed that a procedurally optimal response is an appropriate legal mechanism for addressing conflicts between parents and providers as to end-of-life decision-making for neonatal and pediatric patients.

when parents as well as the physician feel that hastening death or not prolonging life is in the best interest of the child.”¹⁰¹

Similarly, Doron et al. examine the ethical issues surrounding delivery room resuscitation decisions for extremely premature infants. They observe that “[e]xtremely premature infants often die, or survive with severe handicaps, despite receiving invasive and costly medical care.”¹⁰² As such, “[n]eonatologists have been criticized for overtreating these infants, generating huge expenses and causing unnecessary suffering while merely postponing death or prolonging lives with devastating disabilities.”¹⁰³

It is worth noting that the van der Heide et al. article is Dutch, and may reflect Dutch ethical mores, which may differ from an American ethos (assuming such a phenomenon exists). However, it is also worth noting that other studies confirm the paramount value placed on the preservation of life as to neonatal patients: “whoever (physician or parents) prefers more treatment determines the amount of treatment provided at delivery.”¹⁰⁴ Insofar as van der Heide et al.’s analysis reflects general practice, it does seem to be ethically problematic. In essence, it stymies some of the efficacy of DNR orders if they may only be entered when the parents and the physician agree on their necessity. This is because there is no clinical, ethical, or legal controversy where the parents or surrogates and the physician concur on the need for a DNR order. The clinical ethical dilemma only arises where the parents and the physicians disagree on the need for the DNR order.

The physician owes a duty of care to the physician’s patient, and it is difficult to see how the physician is acting in the best interests of the child if the “preservation of life when possible” results in the prolongation of suffering for the patient. The physician who simply acquiesces to the parents’ wishes, whatever those wishes may be, runs the risk of compromising the ethical duties owed to the patient. This concern, of course, is not unique to DNR orders, but attends much end-of-life decision-making, and is partly why the duty and responsibility for medical interventions ultimately rests with the treating physician.

What is unique to the topic at hand is the fact that neonatal and pediatric patients tend to inspire even greater reluctance to discuss

¹⁰¹ van der Heide et al., *supra* note 42, at 418.

¹⁰² Doron et al., *supra* note 86, at 574.

¹⁰³ *Id.*

¹⁰⁴ *Id.* at 580.

and implement DNR orders than most other patient populations, and the fact that physicians and other members of the care team are likely to display greater reluctance to differ with parents.¹⁰⁵ Jonathan Roland's case quite clearly demonstrates this feature of DNR scenarios as to pediatric patients. Doron et al. go so far as to raise the possibility that "the initiation of treatment [for extremely premature infants] is the point of no return, after which parents and medical staff become so attached to an infant that they cannot recognize or withdraw ineffective treatment."¹⁰⁶

Again, this is not to suggest that the treatment team ought to feel no compunction about entering DNR orders for neonatal patients contrary to parents' wishes. Quite the contrary, the prospect of a dying infant would necessarily seem to suggest extreme caution and prudence before deciding to disagree with the infant's parents over as enormous a question as the manner of the infant's death. Hence, the fact that, in one study, "doctors usually honored parents' wishes for resuscitation, even when they preferred to withhold treatment,"¹⁰⁷ is neither surprising nor necessarily problematic. Indeed, it may reflect sound practice.

However, such caution and prudence ought not devolve into sheer capitulation for the wishes of the parents regarding the entry of a DNR order. Doron et al., while cautioning that the prognosis of an extremely premature infant is highly uncertain at delivery, do observe that "[d]ecisions to resuscitate fueled by parents' desires to initiate life-sustaining treatment raise the question of whether ineffective treatment provided solely for the parents' sake constitutes overtreatment."¹⁰⁸

The above discussion should suggest that effective communication between the physician and the parents is crucial. Doron et al. posit that "simple physician-parent communication before the delivery of an extremely premature infant—whether or not there is initial disagreement about the preferred level of care—might decrease the amount of overtreatment."¹⁰⁹ This again demonstrates the ethical dimension of effective communication in end-of-life scenarios for neonatal and pediatric patients.¹¹⁰

¹⁰⁵ Hill, *supra* note 2, at 1–2; Doron et al., *supra* note 86, at 576.

¹⁰⁶ Doron et al., *supra* note 86.

¹⁰⁷ *Id.* at 579.

¹⁰⁸ *Id.* at 580.

¹⁰⁹ *Id.* at 579.

¹¹⁰ Einav et al. adopt a similar recommendation regarding end-of-life decision-making for adult patients, concluding that "[c]ommunication between the patient and his family re-

III. CONCLUSION

To sum up, several themes emerge from analysis of the ethical issues that attend DNR scenarios for neonatal and pediatric patients. First, such patients are ethically unique. While general analysis and practice as to DNR status for adult patient populations may be germane, it is imperative that the care team and/or the ethicist be aware of the differences, in perception and practice, between neonatal and pediatric patients and adult patients. Second, the communications between the care team or physician and the parent *qua* surrogate take on great ethical significance. Effective communication can obviate or even eliminate ethical quandaries before they even arise. Understandably, frank communications as to DNR status of neonatal and pediatric patients with the patients' respective parent(s) is exceedingly difficult, but this does not lessen the imperative to engage in such discussions.

Third, the treating physician's ethical responsibility is primarily owed to the patient, not to the parents. While due caution is obviously needed prior to lodging disagreement with parents' decisions as to the DNR status of their child, automatic acquiescence to the parents' wishes may run afoul of ethical obligations owed to the patient. While "preservation of life" is and likely ought to be the dominant principle of neonatology, the risk of prolonging the suffering of neonatal patients like Angela may be a consequence of stubborn fidelity to that principle. Greater flexibility, even in the face of parents faced with the prospect of losing their infant, ought to be part and parcel of the physician's ethical compass in these matters, as difficult as that may be.

Ultimately, further analysis of these complicated ethical, clinical, and social problems is warranted, as is further education

garding end-of-life decision-making should be treated as a medical skill. These skills need to be taught with the same perfection and attention to detail as clinical procedures." Einav et al., *supra* note 14, at 228. I tend to believe that the notion that communication skills are learned behaviors that require formal training and education is important. In his seminal book, *THE SILENT WORLD OF DOCTOR AND PATIENT*, Jay Katz argues that "[i]t is dangerous nonsense to assert that in the practice of their art and science physicians can rely on their benevolent intentions, their abilities to judge what is the right thing to do . . . supposedly acquired through on-the-job training. It is not that easy." JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* xlvi (John Hopkins Univ. Press 2d ed. 2002) (1984). While time and space do not permit me to explore this topic in detail in this paper, inasmuch as my argument that there is an ethical dimension to communication has merit, a possible next step would be to consider methods of enhancing such communication.

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and training, to equip physicians and ethicists with the tools to initiate DNR discussions with parents of neonatal and pediatric patients well before the child dies.

