

Unilateral Pediatric “Do Not Attempt Resuscitation” Orders: The Pros, the Cons, and a Proposed Approach

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ABBREVIATIONS

CPR—cardiopulmonary resuscitation
DNAR—do not attempt resuscitation

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abstract

A unilateral do not attempt resuscitation (DNAR) order is written by a physician without permission or assent from the patient or the patient’s surrogate decision-maker. Potential justifications for the use of DNAR orders in pediatrics include the belief that attempted resuscitation offers no benefit to the patient or that the burdens would far outweigh the potential benefits. Another consideration is the patient’s right to mercy, not to be made to undergo potentially painful interventions very unlikely to benefit the patient, and the physician’s parallel obligation not to perform such interventions. Unilateral DNAR orders might be motivated in part by the moral distress caregivers sometimes experience when feeling forced by parents to participate in interventions that they believe are useless or cruel. Furthermore, some physicians believe that making these decisions without parental approval could spare parents needless additional emotional pain or a sense of guilt from making such a decision, particularly when imminent death is unavoidable. There are, however, several risks inherent in unilateral DNAR orders, such as overestimating one’s ability to prognosticate or giving undue weight to the physician’s values over those of parents, particularly with regard to predicted disability and quality of life. The law on the question of unilateral DNAR varies among states, and readers are encouraged to learn the law where they practice. Arguments in favor of, and opposed to, the use of unilateral DNAR orders are presented. In some settings, particularly when death is imminent regardless of whether resuscitation is attempted, unilateral DNAR orders should be viewed as an ethically permissible approach. *Pediatrics* 2014;133:S37–S43

Prologue

Jackie (not her real name) is a 12-year-old girl with stage 4 glioma that has spread widely, involving the brain and brainstem; she is currently on the hematology/oncology unit. Multiple scans and medical opinions have confirmed that this malignancy is refractory to further treatment and is terminal. She has deteriorated significantly in recent days and is now very sleepy and unable to converse. The medical team feels that respiratory failure is imminent, and if the patient is intubated, progression of her disease to death in the near future is nevertheless inevitable. The attending physician, after agreement with medical and nursing colleagues, met with Jackie's parents, discussed the anticipated course of events, expressed her sympathy, and told them that efforts at resuscitation cannot help Jackie and therefore will not be provided, but every effort will be made to keep her comfortable.

Peter (another pseudonym) is a 4-day-old boy, born at 23 weeks' gestation and weighing 540 g. His course in the NICU has been notable for severe respiratory distress syndrome and pulmonary interstitial emphysema requiring high-frequency ventilation, hypotension requiring pressor support, and a unilateral grade 4 intraventricular hemorrhage. Despite very high ventilator settings, the infant's oxygenation is barely adequate. The medical team has suggested to the mother that, given the poor chance of survival and the significant chance of disability if he does survive, a do not attempt resuscitation order should be considered. The mother has declined, insisting on a full resuscitation in the event of arrest.

A unilateral do not attempt resuscitation (DNAR) order is one written by a physician without the permission or assent of the patient or surrogate decision-maker. The aforementioned cases illustrate disparate settings in which they might be considered. In the case of Jackie, intubation or cardiopulmonary resuscitation (CPR) is never offered, and the parents are not asked to make or verbalize a decision. The possibility remains, of course, that they might nevertheless request it. For Peter, the mother was presented with a choice. A physician who strongly disagrees with her decision might subsequently consider a unilateral DNAR order. Disagreements regarding CPR can often be resolved when physicians use

patience, compassion, and good communication skills. Parents may be overwhelmed by some combination of sadness, anger, confusion, and possibly even a sense of guilt. It often takes >1 conversation, or 1 day, for them to understand and/or accept what is happening. Good communication includes not only explaining things clearly but also listening to parents and trying to understand what feelings or experiences may be influencing their decision. Despite such efforts, however, parents might request CPR in a setting wherein, based on the child's clinical status and prognosis, it seems to the physician to be the wrong thing to do.

Is the implementation of unilateral DNAR orders an ethically justifiable action? What are the pros and cons of such orders? Under what circumstances should they be considered and with what safeguards in place to prevent their inappropriate use? These topics are discussed in the present article.

DYSTHANASIA AND THE RIGHT TO MERCY

Dysthanasia has been defined as “exaggerated prolongation of agony, suffering, and death of the patient” or “merciless prolongation of life.”¹ The term may be unfamiliar to many pediatricians, but unfortunately the phenomenon is not. Medical interventions are sometimes initiated or continued against the better judgment of clinicians, based on the insistence of parents or well-meaning colleagues. Clark, in a recent essay on attempting CPR in terminally ill children, has argued that performing CPR that has no chance of success inadvertently promotes a culture of dysthanasia.^{1,2} It is our sense that, despite legitimate differences on how best to define success, this intuition is widely shared and may be at the heart of the moral distress felt by pediatric caregivers who often feel helplessly complicit in

interventions they perceive as pointless and possibly cruel.

We suggest that each patient has a right to mercy, understood as the right not to be made to undergo painful interventions that are unlikely to offer benefit.³ That right carries an obligation for physicians not to provide such interventions. It could be argued that CPR in the setting of inevitable imminent death violates that right and on that basis should not be performed even if requested by parents. There is disagreement as to whether patients undergoing CPR experience pain,^{4,5} but enough uncertainty exists to make it a legitimate concern. Moreover, should CPR succeed in restoring cardiac rhythm even for a short time, there is the real possibility of ongoing suffering during that time.

For many, the child's right to mercy may be seen to trump the parental right to decide. In addition, the physician's obligation to act in the patient's best interests is seen to trump his or her obligation to respect the parents' wishes regarding many aspects of care, including CPR. Perhaps part of the problem is confusion about the meaning, and the practical usefulness, of the best interests standard.

BEST INTERESTS: BURDENS VERSUS BENEFITS OR AVOIDANCE OF HARM?

How, then, should it be decided what is in the child's best interests? In essence, one weighs the likely benefits to the patient of the proposed treatment against the anticipated burdens. If the benefits outweigh the burdens, the procedure is in the child's best interests. If not, the converse is true. By this approach, when CPR seems to carry some chance of success, that should be weighed against the burdens it might impose (short- and long-term). If CPR offers no chance of success or benefit to the child, then a decision made on the basis of the patient's best interests

standard would almost invariably lead to the conclusion that providing it is clearly opposed to the child's best interests. In that case, resuscitation should not be attempted even if requested by parents, and a unilateral DNAR order would seem appropriate. However, although a patient's best interests are the widely accepted standard for decision-making on behalf of children, there are at least 3 significant problems in its application.

1. Whether the benefits of any intervention outweigh the burdens is most likely a subjective assessment, based in part on one's values. Well-meaning people often disagree. The parents' values should generally prevail, at least up to some critical threshold.⁶ Locating that threshold, and determining which side of it a parental decision is on, is the hard work in applying the patient's best interests standard.
2. Best interests may be the wrong standard. "Avoidance of harm" may be better. We do not generally expect parental decisions regarding their children to strictly conform to a child's best interests standard. For instance, parents are not required by society to send their child to the best possible school they can afford, even if that might be in their child's best interests. Parents are required, however, to provide for the child's education above some minimal threshold, below which the harm done to the child would be unacceptable. As described by Diekema,⁷ this same "harm principle" should apply to parents' medical decisions; they should be followed as long as they do not reach a threshold of harm deemed unacceptable. Application of this principle to the question of CPR suggests that pediatricians should comply with the parental decision, even if it seems opposed to the child's

best interests, as long as providing CPR would remain below the threshold of unacceptable harm.

Viewing the question of unilateral DNAR orders through this lens might make one less inclined to write such an order, but the possibility of unacceptable harm remains a consideration. Unacceptable harms might include pain or perhaps an affront to the patient's dignity.⁸ Indeed, if a child is being made to undergo hopeless CPR only for the benefit of others, such as the parents, this constitutes a violation of the Kantian imperative that one should never be used solely as a means for someone else's ends,⁹ and as such could be an unacceptable harm.

3. The requirement of the best interests standard that only the interests of the patient be considered may be inappropriately narrow. Some maintain that the patient's interests must take precedence over the family's, and the provision of any potentially harmful treatment that is not in the patient's best interests should raise as much concern as the denial of beneficial treatment.¹⁰ However, Hardwig et al¹¹ have argued that the interests of family members are a legitimate factor in medical decisions. Truog⁴ maintains that "although the interests of the patient are always primary, at the end of life there are times when the interests of the patient begin to wane, and those of the family intensify. Family members may live for years with the psychological after-effects and regrets of end-of-life decisions."

By this reasoning, even if CPR was a burden to the child with no discernible benefit, it may nevertheless be permissible if it confers a benefit to family members. Such benefits might include some measure of comfort to parents, in the belief that they did everything they

could to save their child. Or it could relieve them of the sense of responsibility or guilt they might experience should they agree to a DNAR order. A willingness to move away from a strict interpretation of the patient's best interests standard may make one more inclined to accede to a parental request for CPR even if it seems hopeless. A willingness to prioritize avoidance of harm may make one more inclined to impose a unilateral DNAR order. In both cases, the moral principles must be evaluated in light of the facts. The example of DNAR orders for extremely premature infants highlights the potential risks of factual misperceptions.

THE IMPORTANCE OF PROGNOSIS AND THE EXAMPLE OF EXTREME PREMATURITY

If a child is soon to be born who will be too premature to possibly survive, should the neonatologist approach the mother and ask her to agree to a DNAR order? This action seems wrong. Rather, the thoughtful physician would inform the mother gently but clearly that the child cannot be saved, and thus no invasive medical procedures such as CPR will be attempted. Of note, this approach is consistent with the American Academy of Pediatrics' Committee on Fetus and Newborn's most recent guidelines, which state that if the physicians believe there is no chance of survival, resuscitation should not be initiated. Parental preference regarding CPR in such a case is not elicited.¹²

The example of previsible birth is an illustration of which unilateral DNAR is widely, if not universally, accepted in a pediatric setting. It is a cautionary tale as well. The 2006 edition of the American Academy of Pediatrics/American Heart Association guidelines for newborn resuscitation notes that birth at 22 weeks' gestation may be associated with "almost certain" early death.¹³ The fact that survival was essentially not

possible at 22 weeks' gestation was widely believed in 2006. However, although some authors report extremely low survival rates at this gestational age, a multicenter study from Japan found a 34% survival rate among 22-week newborns admitted to NICUs in 2005.¹⁴ A review of major academic centers in the United States showed that survival for those born from 2003 to 2007 at 22 completed weeks' gestation was 6%, but resuscitation was attempted in only 19%.¹⁵ Therefore, the survival rate among those for whom resuscitation was attempted was close to the numbers reported by the Japanese. Among those born in the same US network from 1993 to 2009 at 22 weeks' gestation and >400 g, when resuscitation was attempted, the rate of survival to NICU discharge was 20%.¹⁶

All of these findings suggest that some reports of low survival may be a result of a self-fulfilling prophecy; resuscitation is not attempted due to extremely low survival rates, which may be due at least in part to the rarity of resuscitation attempts.¹⁷ The disability rate among survivors is high, and these numbers do not in themselves indicate that resuscitation should be attempted at 22 weeks' gestation. However, they do illustrate how misunderstandings about data can easily lead to an incorrect belief that resuscitation is physiologically futile. In some settings, physicians who advocate withholding resuscitation may be combining strict concepts of futility with prognostic assessments about quality of life.

QUALITY OF LIFE

Some may describe CPR as futile and therefore choose not to offer it, not based on an assessment of the likelihood of restoring vital signs or survival to discharge but on the assessment that if the child survived, he or she would be left with an unacceptably low quality of life. This scenario is problematic for at

least 2 reasons. First, predictions about quality of life or degree of disability are imprecise. Second, even if one could accurately predict the extent of disability, an assessment of futility based on predicted quality of life involves a value judgment and potentially puts the physician in the position of placing his or her own values over those of the family or the future values of the child. In addition, by invoking the concept of futility, the important discussion of prognosis in light of parental values might not take place.^{18,19} It is possible, for example, that the quality of life believed unacceptable by the physician may ultimately be acceptable to the family and the child. Moreover, in the absence of clarity or agreement about what quality of life should be deemed adequate, there is a risk of arbitrariness and thus injustice if unilateral DNAR is based on quality of life.²⁰ That is, 1 family might be offered CPR while another is not, without a clear justification for this differential treatment.

For these reasons, many who favor unilateral DNAR for cases in which survival cannot be achieved nevertheless oppose it when based on predictions about quality of life. Nelson and Nelson¹⁸ stated >20 years ago that "unless it is reasonably certain that a child's death is proximate, a physician should not make unilateral decisions to forego treatment based on futility." Many would still agree, but it is worth considering that there might be a limit to this understanding.

Could there be a reliably predicted quality of life so poor that physicians would be justified in a unilateral DNAR? What about trisomy 13 or 18? For all of these children, severe neurologic disability is inevitable. At the time of this writing, there is no consensus among US pediatricians as to whether a unilateral DNAR is appropriate for these patients. In the past, these disorders were deemed "lethal," and unilateral

decisions were justified on that basis (ie, physiologic futility). But some of these children can live for years with more aggressive medical care, and thus the term lethal seems inappropriate.¹⁹ Given that fact, for at least some of these children, unilateral decisions will need to be justified by using quality of life predictions. For some clinicians, the predicted quality of life may be so poor that unilateral DNAR is justified.

OTHER POSSIBLE APPROACHES: THE TAILORED CODE AND INFORMED ASSENT

Lantos and Meadow,²¹ in a thoughtful and provocative essay entitled "Should the Slow Code Be Resuscitated?" argue for that approach in some situations. These authors suggest that when death is inevitable and parents cannot bring themselves to agree to a DNAR order, a brief, almost symbolic attempt at resuscitation is reasonable. Rather than "slow code," they prefer the terms "tailored code" or "appropriate code." This action is, in essence, a deception intended to spare parents the distress of having to verbalize agreement with a DNAR order.

To avoid both the procedure and the deception, some have advocated an approach known as informed assent or informed nondissent.²²⁻²⁴ By this approach, parents are informed of the situation, what will and will not be done (specifying that CPR will not), and why. They are not asked to verbalize agreement but are given the opportunity to state their disagreement. If they do not, the physician would write a DNAR order with the understanding that this is consistent with their wishes, while sparing them the distress of having to say so. This approach is essentially that taken in the opening case of Jackie. Kon²² has rightly stated that, "(F)orcing a patient to endure painful, demoralizing, and dehumanizing procedures merely because the family could not

bear to say ‘let her die’ is wrong. It is understandable that many families cannot bring themselves to say these words; it is unacceptable that so many physicians lack the courage and compassion to say them.”

We concur and would add that to give parents the false impression and burden that their decision will determine whether their child dies seems itself to be cruel. But the question remains what to do when parents nevertheless request CPR. Options might include a consultation with the ethics committee, proceeding with the DNAR order over parental objection, or (rarely the best course) appealing to the courts. Depending on the clinical situation, the best option may be simply to give the family some time.

THE SLIPPERY SLOPE

The basic concern with regard to the “slippery slope” in ethics is that allowing a particular act, itself ethically permissible, would lead to other acts that are not. If allowing unilateral DNAR orders in cases in which CPR cannot restart the heart or where death within hours is inevitable seems itself to be permissible but would lead physicians to make broader unilateral decisions based on personal value judgments, this then becomes a problem with allowing any unilateral DNAR orders. The same would be the case if allowing unilateral DNAR decisions led physicians to avoid disclosures and discussions that parents deserve.

The converse slippery slope argument suggests that if physicians are allowed or expected to perform CPR to placate parents, in a setting wherein it offers no benefit to the child, this action could lead to a similar approach in other treatments, such as mechanical ventilation, chemotherapy, or surgery.²⁵ Of course, in some situations, that is unfortunately already the case. But if one accepts that chemotherapy or surgery with no benefit to the patient should

not be done, or even offered, we see no compelling argument as to why CPR should be different.

LEGAL ISSUES

Legal standards regarding DNAR orders vary markedly from state to state, requiring clinicians to be knowledgeable regarding local standards and to seek the advice of legal experts when encountering difficult cases. Pope²⁶ has described some states as “green light,” meaning they affirmatively permit physicians to discontinue life-sustaining treatment without parental permission. “Red light” states prohibit it, and “yellow light” states provide vague or uncertain guidance. Pope sees the optimum balance in yellow light states, which may provide some of the legal immunity of green light states and the oversight that green light states lack.

Many legal standards reference a standard of care, but standard of care arguments run the risk of circular reasoning: it is legal because it is what most of us do, and most of us do it because it is what the law requires. We suggest, however, that the obligation to adhere to a medical standard is proportional not to the number of physicians who practice it but to the scientific evidence that supports it. Similarly, the obligation to adhere to an ethical standard should be proportional to the strength of the ethical arguments that support it.²⁷

With regard to parental requests for hopeless CPR, Pope²⁶ rightly observes that “most clinicians... provide the inappropriate treatment that surrogates demand. Clinicians are thereby creating and reinforcing the very standard of care with which they do not want to comply.”

CONCLUSIONS AND RECOMMENDATIONS

Thoughtful and intelligent people have articulated strong arguments both for and against unilateral DNAR orders.

Such orders could be seen as a violation of the parents’ right to decide or as a way to spare them the burden of decision. They could support a child’s right to mercy, to be spared a potentially painful or dehumanizing experience that offers him or her no benefit, or be a denial of legitimate interests and needs of the family. They could be a way to avoid a procedure that will not extend life or offer any benefit or as a way for physicians to wrongly impose their own values and avoid difficult discussions with parents. Unilateral DNAR orders could be legal, or not, depending on the jurisdiction.

Taking into account the arguments presented here, we believe that, in certain circumstances, a unilateral DNAR order would be appropriate. For us, as for many others, this would include cases wherein there would clearly be no benefit to the patient of CPR; that is, death is imminent with or without it. The fact that such orders are permissible does not imply that it is never permissible to do the opposite and yield to parents on these matters. As Truog²⁸ has stated, “simple ethical rules and principles may not do justice to the complex dynamics that are often at play in end-of-life care.” The dynamics are indeed complex, but, all things considered, at times it will be best to tell the parents gently but clearly that the child cannot be saved, and treatments that cannot help, including CPR, will not be done. Jackie, the first case presented, may be 1 such example. Newborns who are truly previsible would be another, and this approach is well known and widely accepted in that setting. We see no compelling reason why newborns and older children should be treated differently in this regard.

There are 3 important qualifications to this recommendation. First, one needs to be sure of the prognosis, including consultation with colleagues, before writing a unilateral DNAR order. If there is uncertainty, we need to be honest

about this with the parents and with ourselves. A lack of certainty with regard to prognosis suggests a greater need to give parents options regarding resuscitation. Peter, the second case presented, might represent an example wherein the chance of survival remains unclear enough that a unilateral DNAR order would not be appropriate.

The second qualification is that unilateral DNAR should generally be reserved for true physiologic futility and, with the possible exception of the most extreme cases, should not be written based on quality of life prognosis. We agree with those who feel the latter would give the physician inappropriate power to place his or her values over those of the parents (eg, with regard to disability). Concerns regarding disability are valid and should be shared with parents, but they do not justify a unilateral decision on the part of the physician.

Third, the permissibility of unilateral DNAR orders in certain settings does not eliminate the obligation to discuss the situation, reasonable options, and plans with parents. Although we believe that parents need not be given options that offer no chance of benefiting the patient, collaborative communication²⁹ remains a cornerstone of decision-making for the dying child. Options made available to parents should include consultation with an ethics committee.

Finally, we question the common practice of offering parents a DNAR status, and when they instead opt for a full resuscitation, seeking to overrule their

decision on the grounds that CPR would offer no benefit or be unnecessarily cruel. Physicians must remember that to offer DNAR is to offer a choice regarding resuscitation, even if DNAR is strongly recommended. When parents are given resuscitation as an option and choose it, and the physicians are then upset and seek to overrule that choice, it is very hard to see the parents as the problem.³⁰ At that point, a unilateral DNAR order would require taking away something that was offered, even if the clinical situation is unchanged, which would be far more problematic. Physicians should not offer DNAR status if it would be unethical to withhold CPR. The converse is also true. Full code status should also not be offered if it would be unethical to provide CPR. Thus, we recommend that before DNAR is offered to parents, the physician should be certain not only that DNAR is ethically permissible but also that attempted resuscitation is a permissible option. If the latter is not, then one should seriously consider unilateral DNAR, rather than shifting the burden of the decision onto parents, and then becoming confrontational when they do not agree.

For physicians to issue unilateral DNAR orders would be ethically permissible in certain situations as outlined earlier, but the potential for abuse is real, and proper oversight is essential. Laws that forbid physician discretion in all such cases, even with proper oversight, are misguided, and physicians should seek to change such laws rather than

TABLE 1 Key Considerations Regarding Pediatric Unilateral DNAR Orders

Physicians do not, and should not, have an ethical obligation to provide treatment that offers no benefit to the patient. Rather, the obligation is to compassionately discuss the situation, reasonable options, and what will be done
Asking parents to approve a DNAR order when death in the near future is inevitable may place an unnecessary and potentially significant burden on them
Performing CPR that offers virtually no chance of restoring vital signs may benefit the family in some circumstances, such as providing a desired ritual or giving them the feeling that "everything was tried." It is controversial whether this justifies the potential harms to the patient, such as pain and indignity
A unilateral DNAR order by the physician based on predicted disability risks inappropriately placing the values of the physician regarding quality of life over those of the patient or parents. Thus, unilateral decisions regarding DNAR status should generally be limited to cases of unavoidable imminent death, and perhaps the most extreme cases of poor quality of life, after confirmation of the prognosis and advisability of DNAR with colleagues
The law regarding unilateral DNAR orders varies among states, and physicians should be familiar with the law where they practice

perpetuate practices that they perceive as unethical, inappropriate, or cruel. Offering parents of a dying child any treatment that carries no potential benefits to that child, yet poses the risk of significant harm, is not advisable and should not be required (Table 1).

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