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## **The Culture of Dysthanasia: Attempting CPR in Terminally Ill Children**

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*Pediatrics* 2013;131;572; originally published online February 4, 2013;

DOI: 10.1542/peds.2012-0393

The online version of this article, along with updated information and services, is located on the World Wide Web at:

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American Academy of Pediatrics

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# The Culture of Dysthanasia: Attempting CPR in Terminally Ill Children

## abstract

Both dying children and their families are treated with disrespect when the presumption of consent to cardiopulmonary resuscitation (CPR) applies to all hospitalized children, regardless of prognosis and the likely efficacy of CPR. This “opt-out” approach to CPR fails to appreciate the nuances of the special parent–child relationship and the moral and emotional complexity of enlisting parents in decisions to withhold CPR from their children. The therapeutic goal of CPR is not merely to resume spontaneous circulation, but rather it is to provide circulation to vital organs to allow for treatment of the underlying proximal and distal etiologies of cardiopulmonary arrest. When the treating providers agree that attempting CPR is highly unlikely to achieve the therapeutic goal or will merely prolong dying, we should not burden parents with the decision to forgo CPR. Rather, physicians should carry the primary professional and moral responsibility for the decision and use a model of informed assent from parents, allowing for respectful disagreement. As emphasized in the palliative care literature, we recommend a directive and collaborative goal-oriented approach to conversations about limiting resuscitation, in which physicians provide explicit recommendations that are in alignment with the goals and hopes of the family and emphasize the therapeutic indications for CPR. Through this approach, we hope to help parents understand that “doing everything” for their dying child means providing medical therapies that ameliorate suffering and foster the intimacy of the parent–child relationship in the final days of a child’s life, making the dying process more humane. *Pediatrics* 2013;131:572–580

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### KEY WORDS

cardiopulmonary resuscitation, do not resuscitate orders, do not attempt resuscitation orders, terminal care, end of life care, comfort care, medical futility, withholding treatment, forgoing treatment, medical decision-making, palliative care, advance directives, parent–child relationship, ethics, bioethics, clinical ethics, assent, informed consent

### ABBREVIATIONS

CPR—cardiopulmonary resuscitation  
DNAR—do not attempt resuscitation  
DNR—do not resuscitate  
ECLS—extracorporeal life support

Dr Clark conceptualized the paper, acquired current literature and empirical data, drafted and revised the paper, and completed the final paper for submission; and Dr Dudzinski conceptualized the paper, acquired current literature and empirical data, revised numerous drafts of the paper, and reviewed the final paper for submission.

[www.pediatrics.org/cgi/doi/10.1542/peds.2012-0393](http://www.pediatrics.org/cgi/doi/10.1542/peds.2012-0393)

doi:10.1542/peds.2012-0393

Accepted for publication Oct 19, 2012

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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**FINANCIAL DISCLOSURE:** *The authors have indicated they have no financial relationships relevant to this article to disclose.*

**FUNDING:** No external funding.

The general practice in hospitals is to use an opt-out approach to cardiopulmonary resuscitation (CPR), in which consent is presumed, and CPR is provided to all hospitalized children, regardless of prognosis, unless parents provide an informed refusal.<sup>1</sup> However, we posit that the therapeutic goal of CPR is not merely to resume spontaneous circulation but rather to provide circulation to vital organs to allow for treatment of the underlying proximal and distal etiologies for the arrest.<sup>2</sup> The arguments we make in this paper, while sometimes applicable to other clinical scenarios, refer only to cases in which all treating providers agree that attempting CPR is highly unlikely to achieve this therapeutic goal or will merely prolong dying. We are not referring to cases where there is genuine clinical uncertainty regarding prognosis, outcome, and the ability to treat the underlying disease process. In cases with genuine clinical uncertainty, parents should deliberate with providers about the ethical appropriateness of attempting CPR, because determining the best treatment option depends more heavily on value judgments than on clinical ones.

In cases where attempting CPR is highly unlikely to achieve the therapeutic goal or merely prolongs dying, we should not burden parents with the decision to forgo attempting CPR.<sup>3-5</sup> Seeking parental consent for do not attempt resuscitation (DNAR) implies that attempting CPR has potential clinical benefit that parents choose to forgo and enlists parents to determine whether CPR is good for their child. When parents of dying children consent to attempt CPR, they take on the moral responsibility for choosing a nontherapeutic intervention, thus creating a potential burden for them. This burden is unfair and insensitive to the profound suffering and loss parents of dying children experience,

potentially results in attempting futile CPR, and fosters a culture of dysthanasia, or the “exaggerated prolongation of agony, suffering, and death of the patient.”<sup>6,7</sup>

Rather, physicians should determine whether medical interventions are clinically therapeutic (good) and then enlist parents in determining which of potentially beneficial treatments align with parental values. We are not arguing that parents should be excluded from decision-making, but rather we encourage respectfully including parents in these conversations through informed assent, honoring the special relationships and obligations parents have with their dying children, and recommend that physicians take the primary moral responsibility for the decision to forgo attempting CPR.<sup>8-10</sup> We concur with the palliative care professionals that through a directive goal-oriented approach, physicians frame discussions on the basis of parental goals and hopes for their child, making treatment recommendations within the context of these goals while disclosing the rationale and justification.<sup>11-16</sup> By using this approach, rather than asking permission to forgo CPR, physicians tell parents that they will not perform CPR. Although this approach allows for respectful disagreement, the responsibility of the decision to forgo CPR resides with the physician. We argue that this approach is more humane than our current approach and shepherds children and their parents through a more respectful dying process.

### CLINICAL CASE DISCUSSION

The following clinical cases demonstrate a common predicament for parents of dying children and their physicians: the imperative to cure meets medicine’s inability to do so. After weeks or months of asking parents to authorize painful and invasive

treatments that offered hope of cure, parents are confronted with a starkly contrasting proposition, forgo or withdraw life-sustaining therapies to allow their children to die as peacefully and comfortably as possible.

In these cases, the parents want everything done for their children, which is a reasonable request from any parent.<sup>14</sup> However, based on the extremely low probability of successfully treating the underlying disease process on the basis of empirical evidence and the clinical experience of the providers, the physicians do not ask for parental permission to forgo CPR; rather, they inform the parents that CPR is not medically indicated. As a result, the parents do not have to make a nearly impossible decision. Their children are treated with respect through the provision of therapeutic interventions congruent with parental goals rather than harmful and unnecessary treatments.<sup>12,13</sup>

### Case 1

A 4-month-old boy suffers from a metastatic infantile chest wall fibrosarcoma. During his life-long hospital stay, his tumor causes catastrophic pulmonary hemorrhages that require CPR on multiple occasions. After 4 months of aggressive chemotherapy, his tumor is ultimately deemed incurable by multiple oncologists. Two weeks after his parents are informed of his terminal condition, he remains in the PICU, requiring noninvasive positive pressure ventilation. His parents explain to the new attending physician that they want to be “selfish” and “keep him alive forever”; however, they fear that he will continually suffer from catastrophic hemorrhages, which will be “unbearable” to watch. Carefully listening to the fears and wishes of his parents, the medical providers encourage his parents to focus on the hopes and goals they wish to achieve during his

remaining life.<sup>12,13</sup> Rather than “requesting a DNAR,” the providers gently inform them that attempting CPR is not medically indicated. Several hours after the goal-oriented conversation, his parents request to take him outside for the first time in his short life. He dies several hours later, peacefully in his mother’s arms.

## Case 2

An 8-month-old boy with Adams-Oliver syndrome, a rare genetic disorder consisting of telangiectasias, terminal limb defects, vascular anomalies, and occasionally congenital heart disease, is admitted with failure to thrive. Within 1 month of his hospitalization, he requires transfer to the PICU for respiratory failure. At the time of intubation, he suffers from cardiac arrest, requiring emergent cannulation onto extracorporeal life support (ECLS). Cardiac catheterization reveals severe pulmonary hypertension secondary to hypoplastic and stenotic pulmonary veins. The lesion is not amenable to surgical or medical intervention. Despite the providers’ predictions, he survives decannulation from ECLS, although he remains on mechanical ventilation and inotropic support. His parents request that the medical team continue to do “everything” for him.<sup>14</sup> While his providers humbly agree to continue mechanical ventilation and inotropic support, they inform the parents that attempting CPR in the setting of cardiac arrest is not medically indicated because the underlying pathophysiology cannot be treated.<sup>17</sup> Three months later, when he develops refractory hypoxemia, his mother holds him in her arms, requests extubation, and allows him to pass peacefully. After his death, his parents report how they cherished the last 3 months of their child’s life in the PICU and are extremely appreciative that “everything was done” for their child.

## *Presumptive Consent to Resuscitation and Futile CPR*

Unlike most medical conversations in which we obtain informed consent to provide an intervention, we seek informed consent to withhold CPR. This paradigm shift originated in the 1970s as a result of the inability of the medical profession to document mortality and morbidity outcomes or to provide clear guidelines and indications for CPR.<sup>2,18–20</sup> This model of presumed consent for CPR in the inpatient setting promoted the societal expectation that all patients are entitled to CPR regardless of potential therapeutic benefit.<sup>2,19,21–23</sup> In the era of informed consent and medical optimism, the societal expectation of universal CPR has led the medical community to justify attempting futile CPR or CPR that likely will not achieve the therapeutic goal and will merely prolong dying, based on the symbolic nature of CPR and the potential benefit to the parents.<sup>7</sup> This justification of futile CPR inadvertently promotes a culture of dysthanasia.<sup>6</sup>

## *Ethical Rationale for Not Performing Futile CPR on Children*

Some contend that performing futile CPR is not always harmful, because the “child is beyond suffering,” but this is a belief, not a fact, with dire consequences if we are mistaken.<sup>7</sup> Furthermore, not all children who are dying have neurologic involvement. Under these circumstances, sedatives and analgesics should be used for comfort but not to palliate pain reluctantly inflicted by health care providers who attempt CPR to benefit the parents and not the child.

Some ethicists justify futile CPR on the basis of an ethics of care, arguing that performing futile CPR is not always wrong because it is a “sincere act of caring and compassion” toward parents.<sup>7</sup> However, Ross explains that

“A child cannot be treated solely as a means to achieve someone else’s goals and ends but must be treated simultaneously with respect to her own actual and developing goals and ends.”<sup>24</sup>

Furthermore, this justification may persuade providers to administer slow codes, which lack urgency and swiftness, or show codes, short vigorous resuscitations, in an attempt to prevent harm to the child, while demonstrating respect for parental authority.<sup>25–27</sup> Lantos argues in favor of this “symbolic resuscitation” as a compromise between the “tragic reality [of death] and illusory hope [that the child will not die].”<sup>25</sup> However, “symbolic resuscitation” is an act of deception. In fact, the concept of writing do not resuscitate (DNR) orders partially originated from the fact that slow codes and show codes were performed without informing patients.<sup>2,19</sup> Frader argues that performing a symbolic resuscitation is ethically indefensible because it “fails to respect the importance of trust and fidelity [physicians] owe all persons.”<sup>25</sup> Furthermore, Kodish argues that supporting symbolic resuscitations may lead to “an erosion of trust and a cascade of problematic consequences...If you are going to do something, do it right.”<sup>25</sup> Even though the news may be distressing, most parents want the truth, not false hope, and performing futile CPR potentially perpetuates false hope.<sup>28</sup>

## *Futility: Defining the Goals of CPR*

We agree that determinations of medical futility are value based, and the concept and its application have been debated for decades. However, we argue that it remains a recognizable phenomenon in clinical medicine.<sup>4,29–32</sup> Determinations of medical futility are intervention specific and related to the goal of the intervention.<sup>33</sup> We define the goal of CPR as providing circulation to

vital organs to allow for treatment of the underlying proximal and distal etiologies of cardiac arrest. Using this definition, however, does not necessarily mean that CPR has to allow the child to make a full functional recovery; rather, it allows time for potential treatment of the underlying proximal and distal causes of cardiopulmonary arrest.<sup>2</sup> When there is agreement among treating clinicians that CPR is highly unlikely to achieve this goal based on medical knowledge, clinical expertise, and professional experience, CPR is medically futile, and it is ethically permissible to withhold it.<sup>4,32</sup>

We agree with the American Academy of Pediatrics policy's stronger stance regarding CPR in dying children. "It is inappropriate for life-prolonging treatment to be continued...when the treatment is judged to be harmful, of no benefit, or futile."<sup>34</sup> Justified by our professional obligations, we believe that authority for determining the therapeutic benefit of CPR appropriately resides with the treating physicians, and agreement should be reached among treating clinicians about the futility of CPR before invoking informed assent. If such agreement cannot be reached, this may be an indication that the benefit of CPR remains clinically uncertain—a category of cases we do not address in this paper. Granted, in making all medical decisions, physicians must embrace uncertainty, prognostic and otherwise.<sup>17</sup> Bishop et al<sup>2</sup> explain:

Such candor on the part of the medical community could begin with our admission that not all interventions are medically feasible...the unintended consequences of our successes are practices like in-hospital universal, presumed consent to CPR that result in patient expectations on which medicine cannot deliver.

### *Our Professional Obligations as Pediatricians*

Arguments against the rights of physicians to withhold medically futile

treatments note that any such determination is both a medical and a value judgment, particularly given inevitable prognostic uncertainty. As Youngner<sup>35</sup> noted:

"I would argue, however, that all except for physiological futility and absolute inability to postpone death, also involve value judgments... Physicians should not offer treatments that are physiologically futile or certain not to prolong life... Beyond that, they run the risk of 'giving opinions disguised as data.'"

This risk can be mitigated when physicians are honest with themselves and parents about distinguishing empirically based judgments from value judgments. Tomlinson and Brody's argument is more compelling, arguing that acting on these professional and value judgments is within the scope, even the professional obligation, of physicians. Physicians frequently limit surrogate demands for treatment, particularly when a physician determines that the harms outweigh the benefits.<sup>36</sup> Surgeons make this appeal when they refuse to operate.

"To assert that the physician should not have this discretion is to deny that the medical profession should have any power to interpret and apply its own defining values, in this case the duty to do more good than harm to patients.... [Physicians] retain the moral authority to make some decisions about the purposes to which his or her skills can be put."<sup>36</sup>

We agree with Tomlinson and are not troubled that physicians make value judgments when they choose to withhold CPR because this is a ubiquitous aspect of the practice of medicine.

### *Legal Precedent: Respect for Parental Authority*

However, the medical standards for obtaining parental consent to forgo attempting resuscitation inevitably influence legal standards, prioritizing respect for parental authority in decision-making regarding resuscitation.<sup>37–39</sup> In *Matthew W*, a dispute regarding CPR for a child with

a severe brain injury from non-accidental trauma, the Supreme Court of Maine emphasized that parental rights superseded the doctors' authority to write a unilateral DNAR (ie, written over parental objection), stating

Exercise of a do not resuscitate directive over parents' objections not only infringes upon the fundamental rights of parenthood, but could have the effect of conclusively preventing parents from raising their child or ever again exercising their fundamental rights.<sup>39</sup>

In the case of *Jane Doe*, a 13-year-old girl who suffered from a progressive and devastating degenerative neurologic disease, the Supreme Court of Georgia ruled that both parents must agree to a DNAR order, otherwise the hospital "must follow the statutory presumption that every patient is presumed to consent to resuscitation."<sup>37</sup> Finally, in the case of *K.I., B.I., D.M.*, the court affirmed that the "wishes of the natural parents are controlling" unless the parents have not acted in the best interest of the child, as in child neglect cases. Under these circumstances, judiciary involvement is required to determine whether a physician may write a unilateral DNAR order.<sup>38</sup>

### *Role of Parental Decisions to Limit Resuscitation*

The courts' respect for parental decision-making is understandable. In a culturally, ethnically, and religiously diverse society, we generally demonstrate "respect for persons" by deferring to the autonomy of parents as ethical and legal decision-makers. Whether parents request everything or consent to DNAR, we assume parents are acting in their child's best interest.

However, compared with the adult literature, there is a paucity of empirical data regarding decision-making about pediatric DNAR orders. Although several recent epidemiologic studies report that most children die in the

hospital, one-third of whom have a DNAR order, the empirical data regarding the impetus, rationale, or content of DNAR orders in children are sparse, despite the emphasis on the process and content as described in the palliative care literature.<sup>12,13,40–54</sup> A few policy statements by the American Academy of Pediatrics address DNAR orders; however, none specifically guide medical providers on the timing, process, or content of DNAR discussions.<sup>41–43</sup> Adding to the complexity of the process, the data regarding empirical outcomes after cardiac arrest in children remain limited, emphasizing good and bad neurologic outcomes (functional status) and survival to discharge from the hospital without analyzing morbidity in detail or the experiences lived by families of survivors and nonsurvivors of cardiac arrest.<sup>55–58</sup>

Despite the paucity of empirical data regarding the role of parents in decisions to limit resuscitation, we argue that placing the weight of this decision on parents is not justifiable because of the intimacy of the parent–child relationship. Although Ross argues that parents are obligated to refuse treatment if the burden greatly outweighs the benefits, Nelson explains “Often, the consistency between loyalty to a child and allowing the child to die is not immediately obvious to many parents.”<sup>4,24</sup> Paris et al states “Physicians do the parents no favor by asking them to decide whether or not to attempt ‘futile’ CPR...to attempt to push the burden of a decision to omit a non-beneficial intervention onto the shoulders of the patient or patient’s family would be ‘shirking [one’s] duty’ as a doctor.”<sup>5</sup> Nelson et al explains further: “Some physicians present all technically feasible options to the parents of a critically ill child and offer to do whatever the parents want. . . Such ‘vending machine medicine’ is inconsistent with good medical prac-

tice.”<sup>4</sup> Lamas and Rosenbaum state “a physician who merely spreads an array of vendibles in front of the patient and then says, ‘Go ahead and choose, it’s your life’ does not warrant the...distinguished title of doctor.”<sup>3</sup>

Although Michelson et al show that more than half of parents would not rely on their “physician-estimated prognosis” in the hypothetical situation of “asking the doctors to stop the use of medicines or machines,” data involving parents who actually had to make end of life decisions demonstrate that parents appreciate directive support and guidance from their physicians.<sup>59–</sup>

<sup>61</sup> One mother explains:

The doctors helped by giving me options for him not to suffer... Just always talking to me with the truth and telling me their opinion... He was very frank when he told me, “Me, as a physician, my opinion would be to just let him go.” To me that was very, very important.<sup>61</sup>

Furthermore, relieving physicians from providing substantive treatment recommendations within the context of the goals and wishes of the patient is not necessarily justified. Empirical evidence shows most patients prefer to be involved, yet do not necessarily want the primary responsibility of making the decision.<sup>62</sup> Finally, the lack of patient trust in physician prognosis does not absolve the physician from the obligation to be honest and transparent or justify offering medically futile interventions.

#### *Limiting Parental Choices to Therapeutic Options: The Intimate Parent–Child Relationship*

Hence, we argue that pediatricians are professionally obligated to limit choice to potentially therapeutic options, while acknowledging that all medical decisions are value based and have potential uncertainty. Offering the option of futile CPR creates and reinforces the false dichotomy that parents have to choose between either “fighting to the

end” with CPR or “giving up” with DNAR.<sup>63</sup> Yet, one may fight to the end without receiving CPR. The false dichotomy perpetuates the false belief that comfort care is the last-ditch option rather than the best clinical option.<sup>63</sup> Parents who refuse DNAR are not necessarily “choosing” an attempt at CPR; rather they may be opting for the life of their child. As Blackhall explains, many patients who choose CPR are not fully informed about the potential outcome. They are choosing a chance at life.<sup>64</sup>

When there is an abrupt shift from curable illness to terminal illness, parents do not have time to process the information. This sudden shift is cognitively and emotionally disruptive and may lead to parental distrust of new clinical information and recommendations. Parents may become confrontational with the medical team, hoping to prove physicians’ predictions wrong.<sup>65</sup> Furthermore, the loss of control that is associated with hospitalization may force parents to become stronger and more forceful advocates. In one survey, approximately half of parents reported they had “little to no control over the situation during their child’s final days. Parents, in particular, struggle with the loss of control because their traditional roles of protector and provider are seriously threatened and violated during the hospitalization.”<sup>66</sup> Parents, who have shared advocacy for their child during the curative treatment phase, may feel the need to wrest advocacy from health care providers, to defy the medical odds and to opt for any intervention that might delay death.

In addition, although empirical evidence demonstrates that the perspective of the majority of parents identify themselves as key stakeholders in end of life decision-making, explicitly authorizing DNAR amounts to granting permission to let their child die.<sup>5,40,60,61</sup>

This decision is unfathomable for many parents, for the “death of one’s child is particularly devastating when compared with other kinds of deaths.”<sup>77</sup> Even if parents are able to make this decision, parental guilt and grief may be more severe if they have to make the decision to forgo a potentially life-saving intervention. As one parent describes, “The first feeling I got was guilt because it was like I would take away his life support and what if there was a chance that he could have survived?”<sup>61</sup>

Furthermore, the close bonds and inextricable link between the well being of the child and the identity of the parent is a quiet but powerful factor.<sup>67</sup> Because so much of a parent’s energy is devoted to promoting and maintaining the well being of minor children, their child’s illness directly impacts the parental role, for “critical illness threatens the ability of parents to fulfill their familiar and important roles of protecting and providing for their child.”<sup>68</sup> In some circumstances, the very identity of the adult as parent is threatened if their only child dies, making the decision even more challenging.

Additionally, allowing a minor child to die also seems unnatural. Putting parents in the position to forgo CPR may only intensify parental grief and helplessness, because parents are never prepared for the death of their child. Meyer et al explain: “Even families of children who are born with life-shortening conditions cannot truly be prepared, because the death of a child inherently violate[s] the natural order.”<sup>28</sup> A father laments, “No one should have to bury a child.”<sup>69</sup>

Finally, parents’ desperation in the face of a child’s critical illness is often coupled with an unshakable hope for survival. Many parents have accepted invasive and painful interventions for weeks, months, and even years in hopes of curing or prolonging the lives

of their children. Hope has enabled them to “cling to the most optimistic message they have heard, even though it may be far removed from present reality.”<sup>4</sup> Nearing the end of life, they are faced with a contradictory new proposition: forgo or withdraw these aggressive therapies to allow the child to die peacefully and painlessly. Supporting parents in making the shift from hope of cure to hope for a peaceful death is highly complex and may not even be feasible for many parents.<sup>66</sup>

### *Informed Consent in Pediatric Medicine*

In reality, physicians do not require informed consent for every aspect of a child’s medical care. For example, pediatric health care providers do not obtain informed consent to administer an albuterol nebulizer to a child with asthma, to provide antibiotics to a child with pneumonia, or to perform newborn screening. Rather, tacit consent or informed assent is practiced in which parents are informed of the intervention or treatment and the health care provider awaits signs of assent or dissent. Like CPR, the determination that medical interventions are beneficial to a particular patient involves both clinical and value judgments. Absent evidence of dissent, these interventions proceed because of the perceived benefit. Similarly, informed assent for DNR is permissible because health care providers determine that CPR is highly unlikely to be effective or beneficial.<sup>70</sup> If we permit tacit consent to provide treatment, we argue it is also permissible, in the circumstances we outline for withholding a treatment such as CPR. We currently use this argument to withhold ECLS from a child with a poor prognosis without obtaining informed consent or even informed assent.

Furthermore, pediatricians seek judicial assistance if parents make

decisions that potentially harm their children.<sup>71</sup> If a parent refuses a life-saving blood transfusion for their child, physicians enlist the court. Similarly, physicians would seek judicial assistance if parents refused CPR for a minor child suffering from an acute and reversible process. Although we agree with the precedent to respect parental authority, such authority is balanced with the professional obligation to prevent harm and only offer potentially therapeutic options.<sup>59,68,71,72</sup>

### *Assent Versus Consent: A Different Approach to DNAR*

Hence, when there is agreement among treating providers that CPR will not allow for treatment of the underlying proximal and distal etiologies of the arrest or will merely prolong the dying process, physicians should disclose the clinical rationale for withholding an expected yet nontherapeutic intervention based on published empirical data, their experience, and medical knowledge. In other words, they should seek informed assent from parents.<sup>8–10</sup>

By using this approach, physicians take the primary professional and moral responsibility for the decision to forgo CPR. This approach respectfully includes the parents while simultaneously honoring the special relationships and obligations parents have with their dying children as we have described. We do not advocate for a strong paternalistic approach, in which we treat autonomous parents as if they lack the capacity or authority to consent. Rather, we think informed assent is more appropriate.<sup>8</sup> Curtis and Burt describe informed assent: “We envision a process in which clinicians provide full information about the risks and benefits of treatments, convey specific recommendations about the medically proposed course, and clearly indicate that patient and family are entitled to defer to the clinicians’

judgment... [thereby] reliev[ing] them of unwanted burdens of making life-and death decisions.”<sup>8</sup> Kon uses a different term, “informed non-dissent,” to refer to instances where “the clinician makes a decision regarding the DNR status of the patient, and informs the family that unless they object the doctor will write a DNR order.”<sup>9,10</sup> We think both descriptions are appropriate, provided parents are informed, although Kon’s description is more akin to our own.

### *Informed Assent in Practice*

We envision establishing early in the therapeutic relationship the expectation that the physician will make decisive recommendations only when there is clinical evidence and agreement among treating providers that an intervention will likely not be therapeutic and will always enlist parents in choosing among potentially therapeutic treatment options. By helping parents to establish expectations, hopes, and goals, without offering a nontherapeutic option, physicians help parents find ways to opt for life without opting for CPR.<sup>12–15</sup> By calibrating the parents’ expectations, limiting nontherapeutic CPR appears less like a failure or abandonment and more like the actualization of a treatment course that we have helped parents to expect. Physicians reassure parents that the decision to withhold CPR does not mean choosing death. Rather, physicians are choosing to

respect the child and prevent unnecessary interventions that are potentially harmful based on the best of our medical knowledge and experience. Sometimes, death is the reality beyond our control.<sup>7,3</sup>

We suggest that either in tandem with a goals of care discussion or after this discussion, the doctor says something like “We want to provide x treatments because we have good reason to believe they will be helpful and in line with your goals. Throughout these treatments, we will do everything to ensure your child is comforted and treated in x, y, and z ways. We will not perform CPR for the following reasons... I want you to know this ahead of time so you know what to expect. I am making this decision in light of all the goals and hopes you have for your child, based on the consensus of all my colleagues and the current medical knowledge we have. We cannot always predict the future, however I envision the next few days to look like this... What questions can I answer?” Through this approach, parents may recognize that although DNAR is not a choice they could ever opt for, they are empowered to permit the physician to take on the professional and moral responsibility to make this nearly impossible and challenging decision.

### **CONCLUSIONS**

The medical community’s current standard of care in using an opt-out

approach to CPR creates a perceived obligation for physicians to obtain parental permission to forgo CPR in all children.<sup>1</sup> This approach potentially results in justification for attempting futile CPR, fostering a culture of dysthanasia.<sup>7</sup> Yet, in dying children for whom there is agreement among treating health care providers that attempting CPR is futile or will not achieve its intended goal, we argue that physicians have the primary professional and moral responsibility to make the decision to forgo CPR. We recognize that medical decision-making is more complex when providers disagree about the therapeutic benefit of CPR or when the child’s prognosis is more uncertain. However, when treating health care providers agree, informing the parents of the plan to forgo CPR through an informed assent and goal-oriented palliative care approach is clinically and ethically justifiable.<sup>8–10, 12,13</sup> This approach values the special and unique relationship that parents have with their dying children and relieves them from the moral responsibility of choosing to allow their children to die.<sup>6,7</sup> It demonstrates respect and compassion for dying children and their parents, reinforcing physicians’ professional and ethical duty to guide parents through the transition to comfort care as an act of sincere respect and love for their children.

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**HUNTING SEASON:** *Each year in Vermont, the first day of deer hunting is greeted with great fanfare. Generations of men (and some women) head to the woods to swap stories, bond, and bag a deer. The state imposes strict limits; each hunter is allowed to shoot and kill a single deer. According to CNN (U.S.: December 6, 2012), hunting season in Florida can be quite different. The Florida Fish and Wildlife Conservation Commission announced the first 2013 Python Challenge to run from January through early February 2013. The goal is to reduce the number of Burmese pythons in the Everglades. The Burmese python, native to Southeast Asia, was first found in the Everglades in 1979. With no natural predators and a perfect habitat, the python population exploded, and by the year 2000 the python was considered endemic to the Everglades. The huge snakes – a recently caught female weighed 164 pounds and was more than 17 feet long – have practically exterminated many native animal species. Rabbits and foxes are no longer seen and the numbers of raccoons, opossums, and bobcats have dropped as much as 99%. While the importation of Burmese pythons in Florida has been banned, that has done little to curb the population, so the Conservation Commission turned to the public for help and has even offered financial incentives. The prize for killing the most number of pythons is \$1,500 while the prize for killing the longest python is \$1,000. The registration fee is \$25 and hunters must complete an on-line safety course. In contrast to the usual hunter safety course offered in Vermont, the safety course associated with the Python Challenge deals with dangers of hunting pythons. The site also advises that the snakes be killed in a humane manner (e.g., chopping off the head with a machete or shooting the brain). Hunters can only hunt in specific areas of the park off-limits to the public, and road kill cannot be submitted for any prizes. While I recognize that the Burmese python has devastated the native population of the Everglades, the program does sound a bit like the film AVP (Alien vs. Predator). Personally, I am happy that I am living in Vermont and do not have to worry about exotic pythons devastating the woodland environment.*

Noted by WVR, MD

## The Culture of Dysthanasia: Attempting CPR in Terminally Ill Children

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*Pediatrics* 2013;131;572; originally published online February 4, 2013;

DOI: 10.1542/peds.2012-0393

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