

# The decision of “do not resuscitate” in pediatric practice

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## ABSTRACT

يُستخدم الإنعاش القلبي الرئوي حالياً بصورة روتينية لأي مريض مُنوم بالمستشفى ويعانى من توقف القلب أو التنفس. ويُمكن للأطفال المصابين بأمراض مستعصية أو انتكاسية الاستفادة مؤقتاً من عملية الإنعاش هذه ومن ثم الرجوع إلى حالتهم السابقة لاحقاً. ويصاحب عمليات الإنعاش هذه تدخلات جراحية مؤلمة غير ضرورية وقد تترك الطفل في وضع أسوأ مما كان عليه. يعكس قرار الفريق الطبي بعدم استخدام الإنعاش القلبي الرئوي نظرتهُم بعدم وجود أمل في شفاء المريض. يحتوي الأدب الطبي على الكثير من الأبحاث الطبية المتعلقة بقرار عدم استخدام الإنعاش القلبي الرئوي وتطبيقه على البالغين، ولكنها لم تركز على الأطفال. ويناقش هذا المقال حيثيات هذا القرار وطرق تطبيقه من الناحية العملية على الأطفال، كما وسوف يتم تقديم ملخص للتوجيهات المنشورة في مجال طب الأطفال من قبل الكلية الملكية البريطانية والأكاديمية الأمريكية في طب الأطفال.

Cardiopulmonary resuscitation (CPR) is now routinely performed on any hospitalized patients who suffer cardiac, or respiratory arrest. Children with irreversible, or progressive terminal illness may benefit temporarily from CPR, only to deteriorate later on. Painful and invasive procedures may be performed unnecessarily, and the child could be left in a poorer condition. A “do not resuscitate” (DNR) order indicates that the treating team has decided not to have CPR attempted in the event of cardiac or pulmonary arrest. While there is relatively ample literature on this topic in general, there is comparatively little focus on DNR orders as they pertain to pediatric patients. In this paper, various aspects related to the DNR decision making in children will be discussed, and a summary of the published guidelines by the Royal College of Pediatrics & Child Health and the American Academy of Pediatrics will be presented.

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Both pediatricians and parents have the common purpose of restoring health and sustaining the life of the child. Medical advances make it possible to achieve this objective in circumstances previously regarded as hopeless.<sup>1</sup> This capability brings with it considerable clinical, moral, socio-cultural, legal, and economic issues that challenge the values and goals of pediatric care. While these issues arise in many settings, they are most evident in the pediatric intensive care units (PICU). Cardiopulmonary resuscitation (CPR) is now routinely performed on any hospitalized patients who suffer cardiac or respiratory arrest.<sup>2</sup> Consent to administer CPR is presumed because of the urgency of a life threatening situation and since the family decisions may be clouded during such acute situations. The frequent performance of CPR on patients who are terminally ill or who have little chance of surviving has prompted concern that resuscitation efforts may be employed too broadly. Advanced invasive procedures and treatments that may promote and sustain life may not confer any foreseeable benefit, and in fact may cause further suffering to the child and the family.<sup>3</sup> Therefore, CPR may be withheld if, in the judgment of the treating team, an attempt to resuscitate the patient would be futile.<sup>4</sup> However, the practical decision of “do not resuscitate” (DNR) is always difficult and should signal a change in focus towards palliative care.<sup>5</sup> It is important to make sure that the child is as comfortable as possible and in no circumstances is it appropriate to withhold such palliative care. 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 to pediatric patients.<sup>6</sup> In this paper, various aspects of the DNR decision as they relate to children will be discussed. A summary of the published guidelines by the Royal College of Pediatrics & Child Health<sup>3</sup> and the American Academy of Pediatrics<sup>7</sup> will be presented.

**Ethical issues.** The ethical issues that attend the implementation of DNR orders to elderly patients are obviously different than those that are relevant to the neonatal or pediatric patient, who has just begun their life.<sup>6</sup> When DNR is considered, 4 fundamental ethical principles apply: 1) duty of care, 2) partnership of care,

3) legal duty, and 4) respect for children's rights (Table 1). Optimal ethical decision making requires open and timely communication between members of the pediatric team and the family, respecting their values, beliefs, and the fundamental principles of ethics.<sup>3,6</sup> Parents may ethically and legally decide on behalf of children, who are unable to express preferences, unless they are clearly acting against the child's best interest or are unable or unwilling to make such decisions. The wishes of a child who has obtained sufficient understanding and experience should be given significant consideration in the decision making process, for example, include ventilating advanced progressive muscular dystrophy patients. It is now widely accepted in bioethics that a competent patient/family have the right to refuse treatment, even where that treatment may be life-saving or life-sustaining. Resolution of disagreement should be by discussion, consultation, and consensus. The duty of care is not an absolute duty to preserve life by all means (Table 1). There is no obligation to provide life sustaining treatment if the benefits of that treatment no longer outweigh the burden to the patient. It is never permissible to withdraw procedures designed to alleviate pain or promote comfort. For example, withholding hydration, or antibiotics to treat transient infections is not justifiable. These infections may cause distress and pain, and treating them represents an important element of good palliative care.

**Legal issues.** An attempt to resuscitate the patient is considered futile in the absence of a reasonable potential of restoring vital functions. A physician is not legally obligated to make a specific diagnostic or therapeutic procedure available to a patient, even on specific request, if the use of such a procedure would be futile.<sup>8</sup> However, it is important to recognize that there are some disagreements on how futility may be defined, on who defines futility, and on how judgments of futility are applied.<sup>9-12</sup> The potential impact of this variability is highly significant given the recent evidence that perhaps as many as 88% of all DNR orders are based in part on the physician's judgment that resuscitation of the patient would be futile.<sup>13</sup> On the other hand, if a physician wishes to continue treatment of a very ill child, but there is doubt on the benefit, the physician maybe in a difficult legal position if the parents withhold consent. The physician should always act in the child's best interests not on his own beliefs as he will be ultimately responsible for his treatment decisions.<sup>14</sup> Even in countries where ICU care is relatively well developed, considerable differences remain in physicians' attitudes toward end-of-life care.<sup>15</sup> Therefore, the parents should always be participants in the care and decision making process. Older children should be involved to a degree appropriate for their age, experience, and condition. For example, young children who have had several courses

**Table 1** - Fundamental ethical principles when considering DNR (do not resuscitate) decisions.<sup>3</sup>

<p><i>Duty of care</i></p> <ol style="list-style-type: none"> <li>1. Pediatric care has the primary intention of sustaining life and restoring health.</li> <li>2. Whether or not the child can be restored to health, there is an absolute duty to comfort and to prevent pain and suffering.</li> </ol>
<p><i>Partnership of care</i></p> <ol style="list-style-type: none"> <li>1. The pediatric team and parents will enter a partnership of care, whose function is to serve the best interests of the child.</li> <li>2. Children should be informed and listened to so that they can participate as fully as possible in decision making.</li> </ol>
<p><i>Legal duty</i></p> <ol style="list-style-type: none"> <li>1. Any treatment given with the intention of causing death is unlawful.</li> <li>2. Child welfare is paramount and particular regard should be paid to their wishes.</li> <li>3. Parents may make decisions on behalf of children provided that they act in their child's best interests.</li> <li>4. There is no obligation to give treatment that is futile and burdensome.</li> <li>5. Treatment goals may be changed in the case of children who are dying.</li> </ol>
<p><i>Respect for children's rights</i></p> <ol style="list-style-type: none"> <li>1. Each child has the right to the highest standard of health and treatment facilities.</li> <li>2. The child's right of freedom of expression and to receive information of all kinds should be respected.</li> <li>3. A child who is capable of forming his/her view has the right to express those views freely in accordance with age and maturity.</li> <li>4. The families have the right to be given all necessary support in caring for their child and performing their child rearing responsibilities.</li> </ol>

of chemotherapy or organ transplants will often have more informed views on further treatment than adult patients who are considering such treatment for the first time. It should be a duty of the professionals to assess the parent's and child's competency for decision making. Open and timely communication between the parents, patient, and members of the pediatric team are central to informed and ethical decision-making.

**Clinical setting.** In the labor room, neonates should almost always be resuscitated, particularly if there have been no prior discussions on DNR. Examples of clinical situations where DNR may be considered include: multiple congenital abnormalities that are incompatible with survival (for example anencephaly), gestational age of <23 weeks, and severe birth asphyxia with profound brain insult. Examples of conditions where DNR is considered in older children are summarized in Table 2. They may include advanced anterior horn cell disease, severe head injury, advanced incurable malignancy, and brain death.<sup>16</sup> Several studies have shown that children who die after a DNR decision are more likely to have chronic disease, in up to 80% of cases.<sup>17-19</sup> The presence of chronic disease can have a significant impact on a parent's decision to limit treatment and on their ability to cope with that decision. One study showed that parents whose children had chronic disease were more likely to be satisfied with the care at end of life compared with parents whose children had suffered sudden or acute insults.<sup>20</sup> These families may have had more time to reflect and accept the inevitability of their child's death.

**Children with neurological disorders.** One of the most challenging and difficult areas involves the question of withholding life sustaining treatment for children with severe neurological impairment. It is generally accepted to withhold life-prolonging treatment when the quality of life would be so afflicted as to be intolerable to the child. Examples include incurable progressive neurodegenerative, or neurometabolic disorders (Table 2). The quality of life could be considered intolerable when there is little prospect of meaningful awareness and interaction with others or the environment. The DNR decision is more difficult in patients with static (non-progressive) neurological disorders, such as severe cerebral palsy, as they may improve with time.<sup>21</sup> Some of these children have an intolerable burden not only for themselves but also for their parents. Patients with less severe cerebral palsy are even more difficult to assess in regards to the acceptability of their disability. As well, some patients with severe impairment may have a life of good quality. Older children and adults may not view their residual disability as negatively as some normal people do, provided adequate support is available.

Therefore, there must always be a commitment to the provision of high quality care for those with disability. Unfortunately, there are indications that such children have been discriminated against, for example, when they compete for acute surgery.<sup>22</sup> It is important to note that the condition of some of these patients may change with time and can be complicated by recurrent aspiration, or chest infections. The DNR can still be considered in those who require frequent ICU admission and ventilation as their quality of life deteriorates.

**Initial encounter.** When it becomes evident that cure, or acceptable quality of life is no longer possible or expected, the focus of care changes from prolonging life to ensuring a dignified death.<sup>23-25</sup> In acute situations, such as those encountered in PICU, retrospective studies indicated that up to 60% of all deaths follow a DNR decision.<sup>26-30</sup> The intensivist, who is often a stranger to the family, is frequently faced with the responsibility of writing the DNR.<sup>31-33</sup> If such initial encounter occurs in the emergency room (ER), it is always necessary to give life-sustaining treatment first and then review the case. More experienced opinion and observation of the evolution of the clinical state in the light of investigations may further clarify the outcome, which may not be certain initially. All reversible causes for the child's condition must be excluded such as drugs and metabolic abnormalities.

Many pediatricians and parents find the DNR decision psychologically and emotionally difficult.<sup>34,35</sup> It may be easier for the parents to believe that everything possible has been carried out for their child. As well, some physicians may be reluctant to approach the subject of DNR with parents. Their reasons include, unfair to involve the parents in such decision, a DNR decision will not be accepted, or may cause a loss of trust.<sup>36</sup> Religious and cultural issues often play a more vital role in decision making than economic considerations, especially in the Muslim communities.<sup>36</sup>

Discussions with the family on DNR should be conducted in a formal meeting. Meyer et al<sup>37</sup> reported that up to 45% of parents had already considered the possibility of limiting therapy before discussing it with any staff member. This may reflect a shift from a more paternalistic medical attitude to a more family-centered care philosophy in pediatric institutions.<sup>38</sup> Underlining the principles of autonomy and informed consent, the environment may allow families to be more confident in expressing their wishes and thoughts.<sup>39-41</sup> Hence, families may already have a clear position on their opinion before a formal discussion takes place. Such discussions should include the nurses.<sup>42</sup> This encourages a good physician-nurse relationship and strengthens the nature of the bedside relationship between nurses

**Table 2** - Common clinical situations where a DNR (do not resuscitate) decision is considered.<sup>3</sup>

<b>Brain death</b>
Absence of all brain and brainstem functions on neurological examination as a result of acute and irreversible brain insult.
<b>Example:</b> Post cardiac arrest
<b>Chronic vegetative state</b>
A state of unawareness of self and environment in which the patient breathes spontaneously, has a stable circulation, and shows cycles that simulate sleep and waking. The child in such a state is reliant on others for all care.
<b>Example:</b> Post head injury, near drowning, hypoxic ischemic insult
<b>“No chance” situation</b>
Treatment delays death but neither improves life’s quality nor potential. Needlessly prolonging treatment in these circumstances is futile and burdensome and not in the best interests of the patient.
<b>Example:</b> Ventilating advanced incurable neurodegenerative or metabolic disorders
<b>“No purpose” situation</b>
The child may be able to survive with treatment, however, giving the treatment may not be in the child’s best interest. The child may have a degree of irreversible impairment that it would be unreasonable to expect them to bear it. Continuing treatment might leave the child in a poorer condition than already exists with the likelihood of further deterioration leading to poor quality of life.
<b>Example:</b> Ventilating advanced progressive neuromuscular disorders
<b>Unbearable situation</b>
The child and/or family feel that further treatment is more than can be tolerated and they may wish to have treatment withheld or to refuse further treatment irrespective of the medical opinion that it may be of some benefit.
<b>Example:</b> Palliative surgery, or chemotherapy for advanced malignancy

and families. Nurses normally engage in bedside discussion with parents on these issues long before there is an opportunity for the physicians to have the formal meeting.<sup>43</sup> A USA study revealed a high rate of agreement between physicians and nurses on decision making and satisfaction with patients’ treatment.<sup>44</sup> The pediatric residents’ presence in the formal meetings was poor and needs to be encouraged. Family conferences on end of life issues and DNR should be seen as an effective “teachable moment” for staff in training.

**Decision making (Table 3).** Because of the difficulties in accurately predicting the outcome, patients may have a prolonged course in the PICU before a DNR decision is made. Direct neurologic involvement is frequently requested but not needed in all cases. A DNR consensus is achieved with some degree of difficulty in most cases. The DNR decisions are more difficult in younger children, because one must rely on the best interests assessments of others, be they parents, pediatricians, or intensivists. A review of published literature on DNR decisions suggests that there is considerable practice variation around the world.<sup>45-56</sup> In studies

from North America and Europe, 30-65% of deaths in the PICU followed a DNR decision. The numbers may be significantly lower in developing, or under developed countries. The differences in rate of active decision making could reflect either true differences in attitudes and clinical behavior with regard to the management of end of life, or alternatively may be due to different culture, or resource-based PICU admission criteria whereby children with poor prognoses are not admitted.<sup>5</sup>

Lack of benefit from further therapy, and expectation of imminent death is the main rationale for pediatric intensivists forgoing therapy. It is certainly different from quality of life and poor prognosis, both factors quoted by adult clinicians.<sup>57-59</sup> In contrast, for parents, issues such as quality of life, likelihood of improvement, and perception of their child’s pain are the predominant decision making factors. Pediatric intensivists may be more comfortable with the justification of lack of benefit and burden from additional therapy when death seems imminent.<sup>60</sup> A survey among physicians and nurses with hypothetical case scenarios revealed that family

**Table 3** - Summary of the guidelines for the appropriate use of DNR (do not resuscitate) orders.

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- 1- Efforts should be made to resuscitate patients except when circumstances indicate that CPR would be futile, or not in the best interests of the patient.
  - 2- Physicians should discuss the possibility of arrest and encourage parents to express, in advance, their preferences regarding CPR. This should occur in an outpatient setting, or soon during hospitalization, before the patient deteriorates.
  - 3- In young children, a decision may be made by the parents in accordance with the patient's best interests.
  - 4- If in the judgment of the treating physician, CPR would be futile, a DNR order may be entered into the patient's record with the basis for its implementation.
  - 5- DNR orders only preclude resuscitative efforts in the event of arrest and should not influence other therapeutic and palliative interventions.
  - 6- Hospital pediatric staff should periodically review their experience, revise their DNR policies, and educate physicians regarding their role in decision-making.
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CPR - cardiopulmonary resuscitation, DNR - do not resuscitate

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preferences, probability of survival, and functional status are the major determinants influencing decisions on restricting life-support interventions in pediatrics, although there are markedly different attitudes depending on who is in charge of the patient.<sup>61</sup>

Various members of the medical team need to feel part of the decision making process depending on their knowledge, understanding, and experience. Decisions should be made with the parents on the basis of knowledge and trust. Several studies found that parental involvement in the DNR decision making was common.<sup>45-49</sup> However, physicians assume a more paternalistic role in some countries with little or no family consultation in the decision-making process. Studies from South America reported rates of family involvement in the decision-making process as low as 6%. In our Muslim communities, there is evidence that asking parents alone to be explicitly involved or take full responsibility for decisions involving life and death is not culturally or socially acceptable.<sup>36</sup> Presence of extended family, and indirectly sounding out and taking into account their wishes, is more appropriate after assessing the resources and support services available. Ultimately, the clinical team carries the moral responsibility for decision making.

There are different types and intensities of therapy that may be withheld, including CPR, mechanical ventilation, and intravenous inotropic agents. Antibiotics, nutrition and intravenous hydration need to continue to avoid discomfort and pain. Assisted feeding by nasogastric tube or gastrostomy should be considered in a child with a swallowing disorder due to a slowly progressive neurodegenerative disease. It is important to stress that some children go on to survive after a DNR decision. Treatment is withheld because it is futile, but not with the intention to cause death.

**Effective communication.** Talking to families on DNR is very challenging to most physicians.<sup>62</sup> In one study, only 41% of the patients engaged in discussions with their physicians on CPR, and in 80% of the cases, physicians misunderstood the patient's preferences.<sup>63</sup> Frequency of physician communication with families and the quality of information given keeps arising as a significant problem for relatives of dying patients in the ICU, although in one pediatric survey, 70% of parents believed that they were well informed.<sup>64,65</sup> For full involvement, the parents must have adequate information and adequate time to understand and assess it, with time also to obtain alternate advice if they so wish. The final decision is made though the clinical team, which helps to alleviate the burden of guilt that some parents feel. A full record of communication with the family should be documented in the clinical record. Valuable continuing communication and support maybe given by an involved social worker. As well, it is useful to include the primary pediatrician in the discussion, especially if they have known the family well. If they are not part of the ongoing discussion it is essential to keep them well informed of decisions and particularly of the child's death.

**Difference of opinions.** The last days and hours 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.<sup>6</sup> Because children are viewed as just beginning their lives one would likely infer that parents would display reluctance to agree to a DNR order than surrogates of older patients. Approximately half of the families in adult studies would agree with the DNR decision immediately, or after only one meeting.<sup>57</sup> Breen et al<sup>66</sup> reported conflict between staff and families in 48% of end-of-life discussions, and nearly 50% of families in another survey reported

some form of conflict during their family member's stay in the adult ICU. A strong correlation was found with religious background.<sup>67,68</sup> Even physicians, whose preferences play a pivotal role in such decisions, may express diverse approaches to end-of-life decisions on the basis of their own religious background and country of origin.<sup>69,70</sup> Within multicultural societies, understanding the patient's values, and ethnocultural and religious traditions may improve end-of-life care by reducing the risk of conflicts and allowing more individualized care<sup>71,72</sup> In the Muslim society, this is not a major problem as most families have strong faith and believe that everything is in God's hands. The physician should make the important point of not trying to interfere with the death process once it starts.

In most of our institutions, a favorable opinion of 3 physicians is needed for the approval of a DNR decision. However, when there is disagreement within the medical team or between the team and the family, it is important to analyze its origins. It is possible that it reflects different understandings of the issues and that more time and better communication are needed. However, unanimity on the part of the pediatric team is not essential. If there is anxiety on the degree of certainty behind the medical facts, further investigations could be considered. As well, resolving a difference of opinion between the team and the family is essential and may require a second opinion. Under these circumstances, the family should still be fully supported by the team. Many major medical decisions require a second opinion for legal reasons as well as clinical assurance, such as brain death declaration.<sup>73</sup> This could come from within the team, but if there is a more fundamental disagreement or erosion of trust, an expert opinion from outside the unit may be obtained. This could be organized by the consultant responsible for the care of the child. To secure greater confidence in the independence of the second opinion, the family may wish to arrange this themselves. The family should also be at liberty to change pediatrician and move to another consultant if this is possible. Input from religious advisors or other important sources of support to the family may be helpful. The hospital ethics committees may help in providing mediation and conciliatory functions. However, the legal and professional responsibility for decision making still rests with the consultant in charge of the case. In most cases, with effective communication and adequate time, the pediatric team, and parents will come to agree.

**Support and bereavement.** The pending death of a child is one of the most devastating experiences that parents can have and the quality of care at the end of life and after the child's death can have a major impact on the family's grieving.<sup>74</sup> The family's presence at the

bedside is an important element in the dying process. Although this is an emotionally charged situation, the family presence makes the process a clear and open one and conveys the shared nature of the decision. Each hospital should provide educational material both for staff and parents, taking into account the needs of different cultures. Many families will find their own support in different ways. In some situations, families may prefer to care for their dying child at home. This may be when the focus of care becomes palliative and some period of time at home is anticipated. Careful communication and arrangements need to be made with home health care services. This will ensure that there is adequate support available and good continuity of care.

Like the parents, health care providers will experience a wide range of emotions, both in the short term and over time. Work pressures can interfere with the resolution of these issues and failure to address them can lead to stress, lowered morale, and divisions within the pediatric team. All involved staff need support, however, many may not know how to acknowledge or approach this need. Open discussions can be helpful, and physicians should be encouraged to share their stresses and uncertainties with trainees and nurses. Additional support can be obtained from more senior staff, professional support workers, and religious scholars.

**Future perspectives.** Pediatric staff should have access to continuing education in DNR related ethics and communication. It has been recognized that in a scientifically based education it is essential that the psychological and spiritual dimensions of care are fully considered. Hospitals should have an educational clinical ethics forum that periodically meets to review difficult cases.<sup>75</sup> Child bereavement organizations and parent support groups should be promoted and hence used in providing some of this training. The assessment of ethical issues, communication, knowledge, and approaches should continue to form a mandatory part of the assessment of competence in clinical training. With limited available funds, offering expensive treatments and prolonged ICU care inevitably uses resources that may have been better used elsewhere. It is vital to conduct self-audit over the outcome in PICU and to obtain feedback from the involved families. As perspectives may change with time, such surveys should aim to be continuous. Research is needed in neurologically impaired children to determine what degrees of disability is too burdensome. Undoubtedly, this is an area where it will be difficult to reach a consensus as the burden of disability depends on different perceptions.

In conclusion, The DNR should be considered when the continuation of intensive medical treatment is either futile or inflict unbearable suffering on the child.

Physicians often feel that they have failed patients whose problems persist despite active treatment. However, in some circumstances, to continue life sustaining treatment is to offer care that is no longer in the child's best interest. Appropriate DNR decision depends on accurate knowledge of the child's condition and good relationships with the family. Conflicting emotions can affect the balance of both parental and professional judgment, however, good judgment will usually involve second opinions. The life of those with severe neurological disability is to be highly valued, and they should be offered the best professional care. The DNR decisions should never be hurried and there should always be respect for the child's life and a responsibility to relieve suffering.

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