Opinion 2.215 Treatment Decisions for Seriously Ill Newborns

The primary consideration for decisions regarding life-sustaining treatment for seriously ill newborns should be what is best for the newborn. Factors that should be weighed are (1) the chance that therapy will succeed, (2) the risks involved with treatment and nontreatment, (3) the degree to which the therapy, if successful, will extend life, (4) the pain and discomfort associated with the therapy, and (5) the anticipated quality of life for the newborn with and without treatment.

Care must be taken to evaluate the newborn’s expected quality of life from the child’s perspective. Life-sustaining treatment may be withheld or withdrawn from a newborn when the pain and suffering expected to be endured by the child will overwhelm any potential for joy during his or her life. When an infant suffers extreme neurological damage, and is consequently not capable of experiencing either suffering or joy, a decision may be made to withhold or withdraw life-sustaining treatment. When life-sustaining treatment is withheld or withdrawn, comfort care must not be discontinued.

When an infant’s prognosis is largely uncertain, as is often the case with extremely premature newborns, all life-sustaining and life-enhancing treatment should be initiated. Decisions about life-sustaining treatment should be made once the prognosis becomes more certain. It is not necessary to attain absolute or near absolute prognostic certainty before life-sustaining treatment is withdrawn, since this goal is often unattainable and risks unnecessarily prolonging the infant’s suffering.

Physicians must provide full information to parents of seriously ill newborns regarding the nature of treatments, therapeutic options, and expected prognosis with and without therapy, so that parents can make informed decisions for their children about life-sustaining treatment. Counseling services and an opportunity to talk with persons who have had to make similar decisions should be available to parents. Ethics committees or infant review committees should also be utilized to facilitate parental decision making. These committees should help mediate resolutions of conflicts that may arise among parents, physicians, and others involved in the care of the infant. These committees should also be responsible for referring cases to the appropriate public agencies when it is concluded that the parents’ decision is not a decision that could reasonably be judged to be in the best interests of the infant.

**Opinion 2.22 Do-Not-Resuscitate Orders**

When a patient suffers cardiac or respiratory arrest, attempts should be made to resuscitate the patient, except when cardiopulmonary resuscitation (CPR) is not in accord with the patient’s expressed desires or is clinically inappropriate.

All patients should be encouraged to express in advance their preferences regarding the extent of treatment after cardiopulmonary arrest, especially patients at substantial risk of such an event. During discussions regarding patients’ preferences, physicians should include a description of the procedures encompassed by CPR. Patients’ preferences should be documented as early as possible and should be revisited and revised as appropriate.

Advance directives stating patients’ refusals of CPR should be honored whether patients are in or out of hospital. When patients refuse CPR, physicians should not permit their personal value judgments to obstruct implementation of the refusals.

If a patient lacks the ability to make or cannot communicate a decision regarding the use of CPR, a surrogate decision maker may make a decision based upon the previously expressed preferences of the patient. If such preferences are unknown, decisions should be made in accordance with the patient’s best interests. If no surrogate decision maker is available, an attending physician contemplating a "Do Not Resuscitate" order (DNR) should consult another physician or a hospital ethics committee, if one is available.

If a patient (either directly or through an advance directive) or the patient’s surrogate requests resuscitation that the physician determines would not be medically effective, the physician should seek to resolve the conflict through a fair decision-making process, when time permits. In hospitals and other health care organizations, medical staffs or, in their absence, medical directors should adopt and disseminate policies regarding the form and function of DNR orders and a process for resolving conflicts.

DNR orders, as well as the basis for their implementation, should be entered by the attending physician in the patient’s medical record.

DNR orders and a patient’s advance refusal of CPR preclude only resuscitative efforts after cardiopulmonary arrest and should not influence other medically appropriate interventions, such as pharmacologic circulatory support and antibiotics, unless they also are specifically refused.

Opinion 2.225  Optimal Use of Orders-Not-to-Intervene and Advance Directives

More rigorous efforts in advance care planning are required in order to tailor end-of-life care to the preferences of patients so that they can experience a satisfactory last chapter in their lives. There is need for better availability and tracking of advance directives, and more uniform adoption of form documents that can be honored in all states of the United States. The discouraging evidence of inadequate end-of-life decision-making indicates the necessity of several improvement strategies:

(1) Patients and physicians should make use of advisory as well as statutory documents. Advisory documents aim to accurately represent a patient’s wishes and are legally binding under law. Statutory documents give physicians immunity from malpractice for following a patient’s wishes. If a form is not available that combines the two, an advisory document should be appended to the state statutory form.

(2) Advisory documents should be based on validated worksheets, thus ensuring reasonable confidence that preferences for end-of-life treatment can be fairly and effectively elicited and recorded, and that they are applicable to medical decisions.

(3) Physicians should directly discuss the patient’s preferences with the patient and the patient’s proxy. These discussions should be held ahead of time wherever possible. The key steps of structuring a core discussion and of signing and recording the document in the medical record should not be delegated to a junior member of the health care team.

(4) Central repositories should be established so that completed advisory documents, state statutory documents, identification of a proxy, and identification of the primary physician can be obtained efficiently in emergency and urgent circumstances as well as routinely.

(5) Health care facilities should honor, and physicians use, a range of orders on the Doctor’s Order Sheet to indicate patient wishes regarding avoidable treatments that might otherwise be given on an emergency basis or by a covering physician with less knowledge of the patient’s wishes. Treatment avoidance orders might include, along with a Do Not Resuscitate (DNR) order, some of the following: Full Comfort Care Only (FCCO); Do Not Intubate (DNI); Do Not Defibrillate (DND); Do Not Leave Home (DNLH); Do Not Transfer (DNTransfer); No Intravenous Lines (NIL); No Blood Draws (NBD); No Feeding Tube (NFT); No Vital Signs (NVS); and so forth. One common new order, Do Not Treat (DNT), is specifically not included in this list, since it may unintentionally convey the message that no care should be given and the patient may lose the intense attention due to a dying person; FCCO serves the same purpose without the likely misinterpretation. As with DNR orders, these treatment avoidance orders should be revisited periodically to ensure their continued applicability. Active comfort care orders might include Allow Visitors Extended Hours (AVEH) and Inquire About Comfort (IAC) b.i.d. (twice daily).

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