AMA Code of Medical Ethics

2.2.4 Treatment Decisions for Seriously Ill Newborns

Making treatment decisions for seriously ill newborns is emotionally and ethically challenging for both parents and health care professionals. Decisions must take into account the newborn's medical needs; the interests, needs, and resources of the family; and available treatment options. Decision makers must also assess whether the choice made for the newborn will abrogate a choice the future individual would want to make for him- or herself, i.e., whether the choice will undermine the child's right to an "open future." Providing information and other resources to support parents or guardians when they must make decisions about their child's care and future is a key responsibility for physicians and other health care professionals.

Decisions not to initiate care or to discontinue an intervention can be emotionally wrenching in any circumstance, but may be particularly so for a seriously ill newborn. Physicians are in a position to help parents, families, and fellow professionals understand that there is no ethical difference between withholding and withdrawing treatment—when an intervention no longer helps to achieve the goals of care or promote the quality of life desired for the patient, it is ethically appropriate to withdraw it.

To help parents formulate goals for their newborn's care and make decisions about life-sustaining treatment on their child's behalf, physicians should:

- (a) Inform the parents about available therapeutic options, the nature of available interventions, and their child's expected prognosis with and without treatment.
- (b) Help the parents formulate goals for care that will promote their child's best interests in light of:
 - (i) the chance that the intervention will achieve the intended clinical benefit;
 - (ii) the risks involved with treatment and nontreatment;
 - (iii) the degree to which treatment can be expected to extend life;
 - (iv) the pain and discomfort associated with the intervention;
 - (v) the quality of life the child can be expected to have with and without treatment.
- (c) Discuss the option of initiating an intervention with the intention of evaluating its clinical effectiveness after a given amount of time to determine whether the intervention has led to improvement. Confirm that if the intervention has not achieved agreed-on goals, it may be withdrawn. Physicians should recognize, and help parents appreciate, that it is not necessary to have prognostic certainty to withdraw life-sustaining treatment, since prognostic certainty is often unattainable and may unnecessarily prolong the infant's suffering.
- (d) Initiate life-sustaining and life-enhancing treatment when the child's prognosis is largely uncertain.
- (e) Adhere to good clinical practice for palliative care when life-sustaining treatment is withheld or withdrawn.

- (f) Provide access to counseling services or other resources to facilitate decision making and to enable parents opportunity to talk with others who have had to make similar decisions.
- (g) Seek consultation through an ethics committee or other institutional resource when disagreement about the appropriate course of action persists.

AMA Principles of Medical Ethics: I,III,IV,V