Decision making in end of life of newborn care



Shared decision making at the end of life of newborn care

Introduction: Neonatal intensive care for extremely low birth weight infant is expensive and most of the time there is disagreement between the Neonatologist and the family to make the best decision in the best interest of the patient. There is a reported incidence of pre-term delivery of low-birthweight (PLBW) babies of 37% of all live births in Pakistan To resuscitate the extremely low birth weight (ELBW) baby or withhold treatment is an ethical issue is frequently faced by health professionals.

Situation: A baby boy with 22 weeks gestational age, weighing 0. 7 kg was shifted from labor room to Neonatal Intensive Care Unit (NICU). The baby was the fourth preterm newborn of her mother and was breathing spontaneously. The Neonatologist decided not to resuscitate the baby as there is minimum chance of survival. The parents were not involved in the process while the decision is made. Within one hour, the infant started gasping and his condition deteriorated, he could not maintain his struggle to breathe spontaneously and eventually expired.

Analysis

In the scenario the doctor decided not to resuscitate the infant because of gestational age that is 22 weeks and weight 7kg. In- fact the doctor decided based on risk and benefits of the treatment and probability of morbidity and mortality of the child. Singh (2003) claims that when the death of an infant is unavoidable or probability to live with neuromotor disabilities is more, the decision to withhold treatment is justified. Akhtar (2010) stated that use of advance technology results in prolonging " death" of patients rather than

giving them comfort. The doctor also used paternalism approach to protect the infant from possible suffering that is prolonging death process. Moreover, the doctor also perceived since the parents are emotionally involved with the infant therefore, they cannot take appropriate decision. In addition, the intention of the doctor was the appropriate utilization of scarce resources that are medicine, technology and employee. In public sector hospital all these resources are limited. Ahmed and Shaikh (2008) stated that health budget has always been low and remains around 0. 6% of the total GDP of the country. However, to ignore the legitimate autonomy of the parents was ignored, and they were not granted discretion in decision making. As the baby was precious and if the parents can afford the treatment, their wish should be respected.

Ethical principle beneficence is in conflict

Beneficence. Health care professionals have an obligation to promote health and avoid harm. This principle involves these elements: (1) one ought not to harm; (2) one ought to prevent harm; (3) one ought to remove harm; (4) one ought to promote good. The most important and easiest to practice is doing not harm. Harm to be prevented is discomfort, suffering, disease and its interventions. The good to be promoted is health. The principle of beneficence implies an obligation to assess benefits against harm. If any treatment cause more harm to infant compare to benefit than comfort of the infant should be priority based on this principle. Decision makers are also obligated to assess benefits of the treatment to infant and cost of the treatment and consequences

In this paper my stance is Neonatologist can make better decision for ELBW infants as they are more knowledgeable and experienced.

Argument

Resuscitating ELBW infants is less beneficial compared with harm

In general the treatment outcomes of ELBW infants are very poor therefore, the expenditure of valuable resources must be utilized wisely. Stolz (1998) study findings revealed that median age of ELBW at death was 2 days and 60% of the infants died at the age of 4 days. Moreover, mean charges to produce one survivor were estimated for infant weighing <500 gram is \$250654.

Beauchamp and Childress (2001) suggested that the decision should be make based on principle of utility that produce maximum positive value for maximum people. The action chosen by the doctor was that maximum infants can be benefitted within the available resources. Therefore, the cost of care can be better spend on larger pool of infants who have better chances of survival. It can be saved by setting standards and denying care to ELBW infants whose survival is uncertain. Guideline for the responsible utilization of intensive care as cited in Lorenz (2005) proposed that providing intensive care treatment to infants whose gestational age is below 23 weeks would not be beneficial. Hack et al. (2000) study revealed the result that Very-low-birth-weight participants had a lower mean IQ and higher rates of neurosensory impairments. Thus, the quality of life of ELBW infants who survived after treatment is not good.

Counterargument

Parents are legitimate decision maker and they should be involved in making decision

It is careless and irrational to ignore or exclude the parents, they should be taken in confidence while making medical decision making. It is also important to consider special protection of the infant who don't has the capacity to express his wishes. Therefore, the parent's interest should be honored but importantly assisted. Autonomy of the parents are not respected beside the fact that they have the capacity to decide and make own plan of action. According to Burkhardt and Nathaniel (2008) autonomy denotes liberty to make personal decision. It is also claimed that health professionals violate the autonomy when they believe the right and rational course of action is the one that is match with their standards otherwise they are labeled as incompetence.

Theory of justice implies fairness in treatment. In most of the health care ethics, the most focus principle is distributive justice that is distribution of goods and services. Nathaniel n Burkhardt (2008) Parents argued that their ELBW infants should be treated as other human being. Their small baby also has the equal rights to attain health services as other normal infants have. It is the responsibility of health professionals to make fair decision for infants who have never attained decision making capacity.

Moreover, the wish of the parents to treat may be considered based on libertarian theory. Burkhardt and Nathaniel (2008) maintains that it is the right of the parents to ask for treatment for the infant based on the material principal capacity to pay for treatment to improve health. Recommendations

Care of ELBW is quite expensive and their survival is uncertain therefore, policies regarding care of the preterm related to gestational age and weight should be formulated and implemented on priority. Moreover, to improve antenatal service is a better and cost effective option to solve the problem. In addition, pregnant women who are at risk of preterm delivery should be counseled and taken in confidence for the possible consequences of the treatment. Boyle (2014) Suggested that during counseling parents should be provided information regarding risk of death and disabilities as consequences of the treatment, so that the can make better decision in the best interest of the infant and family. Health care professionals are decision makers can help the family to make adequate decision making

References

Ahmed, J., & Shaikh, B. T. (2008). An all time low budget for healthcare in Pakistan. *Journal of the College of Physicians and Surgeons Pakistan* , *18* (6), 388.

Akhtar, J. (2010). Living wills in health care: A way of empowering individuals. *JPMA. The Journal of the Pakistan Medical Association*, *60* (3), 240-242.

Beauchamp, T. L., & Childress, J. F. (2001). *Principles of biomedical ethics.* (5th ed.). New York: Oxford University Press. Burkhardt, M. &Nathaniel, A. (2008). *Ethics and Issues in Contemporary Nursing* (3 rd ed.) Australia: Delmar.

Hack, M., Flannery, D. J., Schluchter, M., Cartar, L., Borawski, E., & Klein, N. (2002). Outcomes in young adulthood for very-low-birth-weight infants. *New England Journal of Medicine*, *346* (3), 149-157.

Joy Catlin, A. (2000). Physicians' neonatal resuscitation of extremely lowbirth-weight preterm infants. *Neonatal Network: The Journal of Neonatal Nursing*, *19* (3), 25-32.

Singh, M. (2003). Ethical and social issues in the care of the newborn. *The Indian Journal of Pediatrics , 70 (5), 417-420.*

Stolz, J. W., & McCormick, M. C. (1998). Restricting access to neonatal intensive care: effect on mortality and economic savings. *Pediatrics*, *101* (3), 344-348.