

Identifying futility in a neonatal intensive care unit setting

Shabih Manzar, MD, FAAP, Arun K. Nair, MD, FRCPCH,
Mangalore G. Pai, DCH, MD, Saleh M. Al-Khusaiby, FRCPCH, PhD.

ABSTRACT

Objective: Caring for infants born with lesions that are either incompatible with life or conditions that will not allow meaningful survival is an ethical dilemma. Provision of intensive ineffective care to these infants may be labeled as "futile care" which can consume a major proportion of total hospital expenditure. We conducted the present study to look at the extent of futility in a neonatal intensive care unit (NICU) setting.

Methods: All neonates with lesion either incompatible with life or conditions that will not allow meaningful survival admitted during April 2003 to September 2003 in the Neonatal Intensive Care Unit, Royal Hospital, Muscat, Sultanate of Oman, were reviewed to identify futility. Bed days were used as surrogate for extent of futile care and resource consumption.

Results: A total of 355 infants were admitted to the NICU during the study period representing 4452 consecutive patient bed days. Twenty-five infants fulfilled the criteria of futility. Total length of stay of futile group was 317 (7.1%) days as compared to 4153 (92.8%) days in the non-futile group.

Conclusion: The bed occupancy for futile care cases was less than 8% of all the NICU beds suggesting only a small proportion of resource consumption. Based on this, expecting cost savings from further limiting futile care in neonates is not warranted and is negligible. Ethically, we are assured that the majority of the care provided to our sick neonates are appropriate.

Saudi Med J 2005; Vol. 26 (6): 960-963

Recent advances in medical science and use of technologies had resulted in increased survival of extremely low birth weight infants. Irrespective of the compromised long-term outcome of these infants, the expectation of parents had risen up sharply. Similarly, caring for infants born with lesions that are either incompatible with life or conditions that will not allow meaningful survival has become challenging. It has become an ethical dilemma to provide care to these unfortunate infants.¹ Further provision of care to these infants may be labeled as "futile care", as the treatment provided is ineffective and has no overall benefit to the infant.^{2,3} Thus, pediatrician caring for neonates

are faced with an ethical and economical pressure. On one hand, they have to deal with infant's management problems with periodic parental counseling while at the other hand they have to look at the issues of cost and resource consumption. It has been shown earlier that the cost incurred in "futile care" is very high and can consume a major proportion of the total hospital expenditure.^{4,5} In adult intensive care unit (ICU), the significant reduction in the cost has shown to be achieved by identifying and terminating futile care.^{6,7} But in pediatric intensive care units controversial results have been observed.^{8,9} Published data on extent of futile care in the neonatal intensive care (NICU) is

From the Division of Neonatology (Manzar), John Stroger Jr. Hospital, Chicago, *United States of America* (Formerly affiliated to the Royal Hospital, Muscat, *Sultanate of Oman*) and the Department of Child Health (Nair, Pai, Al-Khusaiby), Neonatal Intensive Care Unit, Royal Hospital, Muscat, *Sultanate of Oman*.

Received 9th January 2005. Accepted for publication in final form 3rd April 2005.

Address correspondence and reprint request to: Dr. Shabih Manzar, Division of Neonatology, John Stroger Jr. Hospital of Cook County, 1901 W Harrison St, 4th Floor, Room 4509, Chicago, IL 60612, *United States of America*. Tel. +1 (312) 8644010. Fax. +1 (312) 8649943. E-mail:

scarce.¹⁰ We carried out this study to identify the extent of futile care provided in our NICU setting.

Methods. The NICU at the Royal Hospital in Muscat has 30 beds and provides level III-IV care for all high-risk neonates including general and cardiac surgery. Details of all admission and discharges/deaths are kept both as case files in the Medical Records Department and on the computer database using visual D base. Data were extracted from the computer database and case files. All neonates with lesions either incompatible with life or conditions that will not allow meaningful survival were included in the study. Futility is defined as the extraordinary treatment provided to the unfortunate infants.¹¹ These infants received humane care or palliative care defined as: provision of care to preserve comfort and dignity and to avoid hunger, pain and anxiety. As such use of airway support, artificial ventilation, cardiovascular support by drugs and other emergency medications was considered to be beyond humane care. The study consisted of a period of 6 months, April 2003 to September 2003. Bed days were used as surrogate for extent of futile care and resource consumption, as described in earlier studies. Total admitted days were counted as occupied bed days. In the cases of death on the same day, the stay was counted as one day (one occupied bed day). One day of stay in NICU costs 30 Omani Riyal (approximately \$79 or 48 Sterling pounds). The study was approved by the Institution Review Board and the Ethic Committee. The statistical package (SPSS version 7.5 for windows) was used for statistical analysis including means and frequencies.

Results. A total of 355 infants were admitted to the NICU during the study period representing 4452 consecutive patient bed days. Twenty-five infants fulfilled the criteria of futility while 330 did not. Total NICU beds occupied by futile group were 317 (7.1%) as compared to 4153 (92.8%) NICU beds of non-futile group (317 bed days = 9510 Omani Riyals or approximately \$25,000 or 15,500 Sterling pounds). **Table 1** shows the major categories of diagnosis among the futile infants. **Table 2** shows the length of stay in relation to the diagnosis. Central nervous system anomalies were prominent cause for futility. **Table 3** depicts the details of the bed status of non-futile group. High mortality (80%) was noted among the futile group of infants (**Table 4**).

Discussion. Contrary to the common assumption, we noted that futility in our NICU setting is minimal. The bed occupancy for futile care cases was <8% of all the beds. This is in agreement to the previous reports from NICU.^{8,9}

The major contributory factor in this overall low futility is the decision of withholding therapy in certain cases. The decision was made in accordance to the guidelines and in the 'best interest' of the baby.¹⁵ Problems were encountered in neurological cases. The major factor was initial denial and delayed acceptance at the parental level. This led us to prolong the treatment and defer do not resuscitate (DNR) decision. In a Muslim community, DNR decisions are not easy to make as Islamic biomedical ethics have different perspectives.^{14,15} In our setting, the main problem in taking DNR decision was that the parent alone cannot take decision of life and death, as this is culturally and socially unacceptable. The detailed analysis with the facts and figures concerning DNR decisions has been reported earlier from our institution.¹⁶ One of the main findings of our study was the importance of periodic parental discussions and meetings. Cuttini et al¹⁷ have launched a project, European Union Collaborative Project on Ethical Decision Making in Neonatal Intensive Care (EURONIC) project, exploring more into the subject of transmission of information to parents and ethical decision making in NICU from health personnel perspective in relation to the legal, cultural, social and ethical backgrounds of the 8 European countries. The results of this project will be adding a lot to the ethical concept of NICU care. With regards to the futile care in neonates as compared to pediatric or adult patients, the diagnostic antenatal ultrasound could be of major help in decision

Table 1 - Major diagnostic categories (n=25).

| Type of lesion | n |
|--|---|
| Central nervous system | 8 |
| Grade IV bilateral intraventricular hemorrhage | 2 |
| Congenital hydrocephalus with thin mantle | 2 |
| Neuronal migration defect | 2 |
| Encephalocele/agenesis of corpus callosum | 1 |
| Holoprosencephaly | 1 |
| Cardiovascular system | 5 |
| Hypoplastic left heart | 4 |
| Complex cyanotic heart disease | 1 |
| Respiratory system | 1 |
| Pulmonary hypoplasia | 1 |
| Renal system | 3 |
| Multicystic kidney disease /renal failure | 3 |
| Chromosomal anomalies | 2 |
| Trisomy 13 | 1 |
| Trisomy 18 | 1 |
| Multiple congenital anomalies | 2 |
| Severe birth asphyxia/hypoxic ischemic encephalopathy stage III | 4 |

Table 2 - Bed occupancy in relation to the type of lesion of the futile group of infants.

| Type of lesion | N of infants | Bed days occupied n (%) |
|---|--------------|-------------------------|
| Grade IV bilateral IVH | 2 | 17 (5.3) |
| Congenital hydrocephalus with thin mantle | 2 | 63 (19.8) |
| Neuronal migration defect | 2 | 124 (39.1) |
| Encephalocele/agenesis of corpus callosum | 1 | 1 (0.3) |
| Holoprosencephaly | 1 | 11 (3.4) |
| Hypoplastic left heart | 4 | 11 (3.4) |
| Complex cyanotic heart disease | 1 | 11 (3.4) |
| Pulmonary hypoplasia | 1 | 1 (0.3) |
| Multicystic kidney disease/renal failure | 3 | 25 (7.8) |
| Trisomy 13/18 | 2 | 9 (2.8) |
| Multiple congenital anomalies | 2 | 10 (3.1) |
| Severe birth asphyxia/HIE stage III | 4 | 44 (13.8) |
| Total | 25 | 317 (100) |
| IVH - intraventricular hemorrhage, HIE - hypoxic ischemic encephalopathy | | |

Table 3 - Summary of bed status among non-futile group of infants.

| Month | N of admissions | Total days stayed | Mean \pm SD (Range) |
|--------------|-----------------|-------------------|------------------------|
| April | 58 | 893 | 15.3 \pm 19.5 (2-88) |
| May | 43 | 680 | 15.8 \pm 18.9 (2-77) |
| June | 57 | 586 | 10.2 \pm 14.2 (2-90) |
| July | 56 | 689 | 12.3 \pm 11.8 (2-56) |
| August | 53 | 577 | 10.8 \pm 11.0 (2-66) |
| September | 63 | 710 | 11.2 \pm 10.1 (2-44) |
| Total | 330 | 4135 | |

Table 4 - Outcome of the futile group of infants.

| Outcome | N |
|-------------------------------|----|
| Died in hospital | 20 |
| Discharged home | 3 |
| Transferred to other hospital | 1 |
| Leave against medical advice | 1 |

making. In 4 of the cases, an antenatal diagnosis was available, which made the parental counseling and decision easier. Expecting 100% antenatal ultrasound may not be feasible in our situation as more than half of the cases are referred cases followed up elsewhere. And even if the facility and reporting is available its reliability is questionable because of the variable expertise at other regional hospitals. More efforts should be taken to utilize the benefits of antenatal ultrasound to its full extent. Ethical decisions in NICU, in general, have multidimensional aspects affected by uncertain outcome, physical pain and financial expenditure.¹⁸ But lesions requiring extensive surgical intervention are the one which create real ethical dilemma. Even in best of the centers no standard DNR policy could be followed in such cases.¹⁹ The question in these cases is not that we could treat but the real question is should we treat. Sall²⁰ has looked at this question from a clinical geneticist's perspective. He found a lack of clear communication between the care giving management team and the family. According to his inference, the major obstacle in delaying decisions is the reluctance from the family member to make a concrete decision even in the conditions with grave prognosis, which is in agreement to the findings of our study. The main limitation of our study was that it was from a single center and a retrospective study. Another possible argument could be concerning the definition of futile care and question of salvageability. For example, congenital hydrocephalus with thin mantle should not be viewed as futile or non-salvageable. Similarly, infants with hypoplastic left heart could live with complex multi-staged operations. Premature infants with grade IV intraventricular hemorrhage or severe asphyxia hypoxic ischemic encephalopathy stage III could live longer. But social, religious and financial factors have to be taken into account. Futile care in one community may not be same for other. For example, in a Muslim community highly provocative actions in caring for premature infants cannot be feasibly taken as reported from the West.²¹ Similarly, the appropriate use of term 'futile care and utility' has been questioned in other reports.^{22,23}

In conclusion, we have demonstrated that only small amounts of resources were expended on futile care in our NICU setting. Expecting cost savings from further limiting futile care in neonates is not warranted and is negligible. Ethically, we are assured that the majority of the care provided to our sick neonates are appropriate.

References

- Dunn PM. Appropriate care of the newborn: ethical dilemmas. *J Med Ethics* 1993; 19: 82-84.

2. Schneiderman JL, Jecker NS. *Wrong Medicine*. Baltimore: Johns Hopkins University Press; 1995.
3. Baylis F, Hellmann J. Ethics in perinatal and neonatal medicine. In: Fanaroff AA, Martin RJ, editors. *Neonatal Perinatal Medicine. Disease of the fetus and infants*. Mosby: A Harcourt Health Science Company; 2002. p. 37-48.
4. Ridley S, Biggam M, Stone P. A cost-benefit analysis of intensive therapy. *Anaesthesia* 1993; 48: 14-19.
5. Kirtan OC, Civetta JM, Hudson-Civetta J. Cost effectiveness in the intensive care unit. *Surg Clin North Am* 1996; 76: 175-200.
6. Esserman L, Belkora J, Lenert L. Potentially ineffective care. A new outcome to assess the limits of critical care. *JAMA* 1995; 274: 1544-1551.
7. Atkinson S, Bihari D, Smithies M, Daly K, Mason R, McColl I. Identification of futility in intensive care. *Lancet* 1994; 344: 1203-1206.
8. Sachdeva RC, Jefferson LS, Coss-Bu J, Brody BA. Resource consumption and the extent of futile care among patients in a pediatric intensive care unit setting. *J Pediatr* 1996; 128: 742-747.
9. Goh AY, Mok Q. Identifying futility in a paediatric critical care setting: a prospective observational study. *Arch Dis Child* 2001; 84: 265-268.
10. Graham S. Futile care in the neonatal intensive care unit: Is aggressive care always justifiable? *J Neonatal Nursing* 1999; 5: 23-26.
11. Arras JD. The distinction between "ordinary" and "extraordinary" treatments. In: Murray TH, Caplan AL, editors. *Which babies shall live: Humanistic dimensions of the care imperilled newborns*. Clifton (NJ): Humana Press; 1985.
12. Gemke RJ, Bonsel GJ, McDonnell J, van Vught AJ. Patient characteristics and resource utilisation in paediatric intensive care. *Arch Dis Child* 1994; 71: 291-296.
13. Royal College of Paediatric and Child Health. *Withholding or withdrawing life saving treatment in children. A framework for practice*. London: RCPCH; 1997.
14. Hedayat KM, Pirzadeh R. Issues in Islamic biomedical ethics: a primer for the pediatrician. *Pediatrics* 2001; 108: 965-971.
15. Gatrud AR, Sheikh A. Medical ethics and Islam: principles and practice. *Arch Dis Child* 2001; 84: 72-75.
16. da Costa DE, Ghazal H, Al-Khusaiby S. Do Not Resuscitate and ethical decisions in a neonatal intensive care unit in a Muslim community. *Arch Dis Child Fetal Neonatal Ed* 2002; 86: F115-F119.
17. Cuttini M, Kaminiski M, Saracci R, de Vonderweid U. The EURONIC project: a European concerted action on information to parents and ethical decision-making in neonatal intensive care. *Paediatr Perinat Epidemiol* 1997; 11: 461-474.
18. Meadow WL, Lantos J. Epidemiology and ethics in the neonatal intensive care unit. *Qual Manag Health Care* 1999; 7:21-31.
19. Caniano DA, Hazebroek FW, DenBesten KE, Tibboel D. End-of-life decisions for surgical neonates: experience in The Netherlands and United States. *J Pediatr Surg* 1995; 30: 1420-1424.
20. Sall HM. Neonatal intensive care as a locus for ethical decisions. *Cleft Palate Craniofac J* 1995; 32: 500-503.
21. Tyson J. Evidence-based ethics and the care of premature infants. *Future Child* 1995; 5: 197-213.
22. Capron AM. Baby Ryan and virtual futility. *Hastings Center Report* 1995; 25: 20-21.
23. Anderson B, Hall B. Parents' perceptions of decision making for children. *J Law Med Ethics* 1995; 23: 15-19.