743

EVALUATING END OF LIFE PRACTICES IN 10 BRAZILIAN PEDIATRIC AND ADULT INTENSIVE CARE UNITS

P. Lago¹, J. Piva², J. Othero², P.C. Garcia²

¹Pediatric, ²PUCRS, Porto Alegre, Brazil

Objective: Evaluate modes of death and the treatment offered in the last 48 hours of life to patients dying in 10 Brazilian intensive care units (ICU) in a period of 2 years.

Design and setting: Cross-sectional multicenter study based on medical chart review. The medical records of all patients that died in 7 Pediatric and 3 adult ICU belonging to university and tertiary hospitals in a period of two years were included. Deaths in the first 24 hours of admission to the PICU/ICU and brain death were excluded.

Intervention: 2 fellows of each ICU were trained for filling a standard protocol (Kappa=0.9) to record demographic data and all medical management provided in the last 48 hours of life. The Student *t* test, Mann Whitney, chi-square and relative risk were used for data comparison.

Measurements and main results: 1,053 medical charts were included (59.4% adult patients). Life Support Limitation (LSL) was more frequent in the adult group (86% versus 43.5%; $p < 0.001$). Do not resuscitate order was the most common mode LSL in both groups (75% and 66%), whereas withholding / withdrawing were more frequent in the pediatric group (33.9% versus 24.9%; $p=0.02$). The LSL was rarely reported in the medical chart (52.6% and 33.7%) with a scarce family involvement in the decision making process (23.0% versus 8.7%; $p < 0.001$).

Conclusion: LSL decision is frequent in Brazil but the most common practice is the DNR orders. The decision making process is predominantly centered on the medical perspective, with scarce participation of the family.

744

"ALLOW ME TO DECIDE "! THE DYING CHILD RIGHTS

D. Grebler

Palliative Care Unit, Tel Hasomer, Ramat Gan, Israel

In Israel about 450 children are annually diagnosed with hemato-oncological diseases.

About 150 children die every year from cancer. Palliative care for children is provided in different settings, home, hospitals and in "Bet Wiesel", the supportive care inpatient unit for children which offers various services at different stages of the disease.

We believe that the children have basic rights like: right to privacy, autonomy, open communication, confidence and the right to be treated with dignity; in order to prevent anxiety and isolation in the final stages of life, and facilitate successful treatment.

Difficult ethical dilemmas are encountered in our daily work such as the right to accept or refuse a certain procedure/treatment that in the past rested entirely with the parents or guardian and not with the minor. Rejection of a minor to a medical procedure creates a conflict of values between the child, parents and health care providers. The law in Israel enables a minor to express his intentions, via the parents and thus to accept or refuse the proposed care plan. The ethical question that arises: Would it be correct if the measure of such rights be defined by the minor's age only? Or by the parents and health care providers who are obligated to protect and preserve the sanctity of the child's life?

A "tailor made" care plan is designed based on the child's health condition, wishes and level of understanding considering the parents' expectations and support needs during every decision making process to obtain optimal care.

745

SPIRITUAL APPROACH FOR SICK CHILDREN

O.Y. Al Gibali, M. Khichi

Pediatrics Pediatric Critical Care Medicine, Hamad Medical Corporaion, Doha, Qatar

When a child got ill the patient and his family will be affected in different aspects. The psychological aspect of the family and the spiritual status should

be approach in a way that results in positive consequences in the child health. Many studies showed that spiritual support for the patient improve quality of life, facilitate coping with the illness. Other reseaches concluded that routine inquiry about spirituality should be incorporated into the initial or interim history depend on the culuture. the faith and the bliefs of the family.

we conducted study in which Fivty medical staff shared in answering two main questions :

1- Do you think that spiritual support has any help to patients and families ?

2- Whom do you think is the best provider of spiritual support ?

The basic conclusion of this study is

34 (94%) agreed or strongly agreed that prayer and Doaa supporting the family of critically ill child . 24 (66%) believe it help in cure & strength Doctor-Family relationship. 6 (2%) said this depend mainly on the family bliefs.

46 (92 %) said that the best provider of spiritual support are doctors & or nurses .

2 (4 %) said the religious man. 2 (4 %) said if the case is near end of life, e.g. brain dead or advance stage tumor, is better to be provided by religious man other wise by medical staff.

746

A PRELIMINARY SURVEY: ETHICAL DECISION-MAKING FOR DYING INFANTS IN NICU IN TAIWAN

N.-H. Peng¹, H.-Y. Lee², C.-H. Chen³, S.-L. Liu¹

¹Nursing Department, Central Taiwan University of Sicence & Tech, ²Supervisor in Nursing Department in Chang Bing Show Chwan Memorial Hospital, ³Chief of Diversion of Neonatology in Taichung Veterans General Hospital in Taiwan, Taichung, Taiwan R.O.C.

Purpose: The purposes of this study were to explore the decision-making process for dying infants in the neonatal intensive care unit in Taiwan.

Methods: A retrospective method was used to review charts of infants who died in the NICU between 2002 and 2008. All research data were reviewed for final admission by a researcher.

Results: Sixty-one charts were evaluated in this research. A “do not resuscitate” (DNR) order was considered and written in 41 (67.2%) infants. In seven infants, parents had considered the DNR but no preexisting DNR was entered in the records. Forty-one charts (67.2%) had DNR orders preceding final hospital admission. Eight parents (16%) had allowed discontinuation of ventilator support when they realized the futility of continued care for dying infants. Five infants received a DNR order withholding chest compression but permitting mechanical ventilation. Three infants received a preexisting DNR order withholding chest compression and withdrawing emergency medicines. Three infants received a preexisting DNR order withholding CPR procedures, and withdrawing emergency medicines but permitting ventilator use.

Discussion: Although excessively invasive treatment such as intubation is being offered and may well be harmful to dying infants, most parents hesitated making a critical decision for their dying infant in this research. Further research should study humane and compassionate care and the needs of bereaved parents and help them to make decision.

Keywords: Ethical Decision-Making, Dying Infant, NICU

747

PALLIATIVE CARE FOR CHILDREN AND YOUNG PEOPLE WITH NEUROMUSCULAR CONDITIONS IN YORKSHIRE, UK 1987-2008

L.K. Fraser¹, J. Aldridge², A.M. Childs³, M. Miller², R.C. Parslow¹

¹Paediatric Epidemiology Group, University of Leeds, Leeds, ²Martin House Children's Hospice, Bostob Spa, ³Leeds General Infirmary, Leeds, UK

Background: Martin House Children's Hospice (MH) is located in Yorkshire, UK. It cares for children and young people with life threatening or life limiting conditions diagnosed before the age of 19 years until the age of 35 years. Many neuromuscular disorders are life limiting and therefore these children and young people may benefit from specialist palliative care services.

Methods: Retrospective study using clinical database at MH from 1987 to 2008.