

Selected Abstracts of the 2nd Congress of joint European Neonatal Societies (jENS 2017) • Session “Ethics”

VENICE (ITALY) • OCTOBER 31ST-NOVEMBER 4TH 2017

58th ESPR Annual Meeting, 7th International Congress of UENPS, 3rd International Congress of EFCNI

ORGANIZING INSTITUTIONS

European Society for Paediatric Research (ESPR), European Society for Neonatology (ESN), Union of European Neonatal & Perinatal Societies (UENPS), European Foundation for the Care of Newborn Infants (EFCNI)

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HOW TO CITE

[Abstract's authors]. [Abstract's title]. In: Selected Abstracts of the 2nd Congress of joint European Neonatal Societies (jENS 2017); Venice (Italy); October 31-November 4, 2017; Session "Ethics". *J Pediatr Neonat Individual Med.* 2017;6(2):e060245. doi: 10.7363/060245.

ABS 1

THE DELIVERY OF BAD NEWS: A ONE OR 2-STEP APPROACH? THE CASE FOR TRISOMY 21

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INTRODUCTION

Trisomy 21 (T21, or Down syndrome), is the most common chromosome abnormality among live births (1 in 730 live births) and the most frequent form of intellectual disability caused by a genetic chromosomal aberration. Hence, informing parents that their infant has T21, is a relatively frequent challenge universally facing neonatologists.

METHODS

We present two theoretical different approaches to this issue:

The 1-step approach consists of informing parents as soon as the mother is physically able to hear the news after delivery, even in the delivery suite if possible.

The 2-step approach consists of first informing parents that at routine physical examination there are findings that "may suggest the possibility of a genetic disorder such as T21". On the next day, the discussion may be resumed with the parents to explicitly confirm the clinical diagnosis.

RESULTS

The dilemma in choosing a 1- or a 2-step approach relates to 2 conflicting concepts. On the one hand, parents have the right to receive complete information as soon as possible. On the other hand immediately after birth the parents are joyful and in need to start the process of bonding while the mother is also often exhausted from the labor process and in need of a resting period. The 1-step approach allows to fully fulfilling the parents right to know, while the 2-step approach may be more adapted to allow for recovery from birth and for initiation of the bonding process. This 2-step approach may unduly delay the right to know, but its goals are to prepare for the harsh message, and avoid maleficence.

CONCLUSIONS

The purpose of this work is to weigh the pros and cons of each approach, and attempt to determine which particular cases (depending upon patient population, in particular religion and religiosity, but also culture and customs) would be better addressed by one approach rather than the other one.

ABS 2

NEONATAL ORGAN DONATION: A POTENTIAL NEW DONOR SOURCE FOR CELL AND ORGAN TRANSPLANTATION

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INTRODUCTION

Hepatocyte transplantation (HT) is a promising treatment for liver failure and inborn metabolic liver disease. Compared to whole liver transplantation, HT is less invasive and has fewer side effects. However, progress is limited by the supply of donor organs. Livers rejected for solid organ transplantation are mainly used for HT. Until now neonatal organ donation has not been considered in Sweden. Organ function has been considered immature and the use of brain death criteria is difficult. One goal of the study is to establish a neonatal organ donation program in the Stockholm region and determine if neonatal donors can provide viable and functional organs and cells for clinical HT.

METHODS

Organ donation was considered in children who died during neonatal intensive care in the Stockholm region during 2015-2017. After informed consent, life-sustaining treatment was discontinued in patients with severe multiorgan damage not compatible with meaningful life according to clinical routine. No other treatment or procedures to preserve organ viability was given. Hepatectomy was performed

after declaration of death by indirect criteria per clinical routine. Hepatocyte isolation was performed by two step collagenase perfusion. Viability was assessed using trypan blue exclusion. Hepatocyte function was assessed through intracellular ATP levels, apoptosis, cytochrome P450 activities, phase II-conjugation and ammonia metabolism. The study was approved by the regional ethics committee.

RESULTS

Ten families were asked for donation. Two families declined participation in the study. From the eight families that accepted organ donation, one patient survived. From the remaining seven infants six livers and one hemiliver were procured. Infants were born at gestational age week 35 to 41 and death occurred on day of life 0 to 13. Cause of death included hypoxic brain injury (3), Vena galena malformation (1), *E. coli* sepsis (1), Meckel-Gruber syndrome (1), and anencephaly (1). Warm ischemia time (WIT) ranged from 65 to 310 minutes. Hepatocyte viability was $83 \pm 16\%$. One neonatal tissue, characterized by prolonged WIT and sepsis, resulted in no viable hepatocytes and was not further analyzed. Hepatocytes associated with shorter WIT showed good drug metabolism activity, phase II activity and intracellular ATP levels compared to our historical control (> 100 adult livers).

CONCLUSIONS

Neonatal organ donation is feasible. Neonatal donors can provide hepatocytes of good viability and function. Hepatocyte viability seems to be associated with cause of death and WIT. Neonatal hepatocytes may be very useful for clinical transplants.

ABS 3

HEALTH CARE PROFESSIONALS' AND PARENTS' ATTITUDES TOWARD PARENTAL AUTONOMY AND THE BEST INTEREST OF THE EXTREME PRETERM INFANT: A NATIONAL STUDY IN SWITZERLAND

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INTRODUCTION

In pediatrics, and specifically neonatology, the “best interest” standard is the core ethical principle in

surrogate decision-making in which the best interest of the infant functions as a guide for decision-making. Some ethicists argue that parents should be the final decision-makers, yet others point to health care professionals (HCPs) because they are better at estimating the child’s best interest. Often it is stated that parents should have the possibility to take end-of-life (EOL) decisions together with the health care team, unless they are not in the child’s best interest. Controversy arises when parents and the health care team view the child’s best interests in a different way. This study aims to further elucidate these issues by providing a nuanced understanding of the nature and experience of HCPs and parents’ involvement in EOL decisions for extreme preterm infants.

METHODS

This is secondary analysis of a nationwide study conducted in Switzerland using mixed methods. This analysis appraises the issue of the best interest of the infant based on (1) a questionnaire for HCPs working in nine level III NICUs and, (2) twenty parental qualitative interviews with parents who lost an extreme preterm infant in the delivery room or NICU of the University hospital in Zurich.

RESULTS

Our analysis illustrates a tension between HCPs and parental attitudes on the best interest of the infant. More than half of HCPs believed that parents should have the opportunity to take part in the decision-making process. HCPs further believed the child’s best interest alone was the basis for decisions about initiating, withholding or withdrawing neonatal intensive care, however, a majority of HCPs did not consider parents as the best judges of what is in the child’s best interests. Parents’ experienced their participation in EOL decisions diversely. Few parents recalled being actively involved in the decision-making. Other parents experienced a dissociative state of mind, which hindered their involvement, whereas a minority of parents felt actively involved.

CONCLUSIONS

Our findings show evidence of the diverging opinions and experiences from HCPs and parents in EOL decision-making for extreme preterm infants. Our study raises the question as to who should assess the best interests of the child. Despite the prevailing attitude of involving parents in EOL decision-making, it has remained difficult to implement a truly shared decision model in practice. We suspect this relates to the confusion around the implementation of a best interest assessment. This study calls attention to the tendency of HCPs to consider themselves as the best stakeholders to assess the best interest of the infant,

which might constrain efforts of shared decision-making that aims to include the perspective of family autonomy. Ideally, the best interest assessment should include the family’s perspective.

ABS 4

CHANGING PARENTAL PERCEPTIONS IN TRISOMIES – A POTENTIAL ETHICAL DILEMMA FOR NEONATOLOGISTS?

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INTRODUCTION

Neonates born with Trisomies have significantly increased mortality and morbidity compared to neonates born without a genetic condition. In the UK, pregnant women who receive an antenatal diagnosis of Trisomy 13, 18 and 21 are counselled and decisions are made regarding the outcome of the pregnancy, neonatal resuscitation and neonatal intensive care. Parents of neonates with Trisomy 13 and 18 are often counselled that these conditions are incompatible

with life. However, parental perceptions are changing with increasing requests for active neonatal treatment. Our aim was to review the trends and outcomes for neonates born with Trisomies at our level 3 neonatal unit over a 9 year period.

METHODS

All antenatal and postnatal diagnoses of Trisomy 13, 18 and 21 that presented to our hospital between 2009-2017 were included. Cases were identified from the locally held antenatal screening database and the national Badger neonatal system. Cases were excluded if the final diagnosis was not of Trisomy 13, 18 or 21 or if neonates were born at a different hospital. Data was analysed for the number of Trisomy cases, pregnancy outcome including fetal demise, feticide, medical termination and still birth. Information was also collected regarding the provision of neonatal resuscitation, admission, neonatal intensive care, ventilatory support and survival.

RESULTS

131 cases of Trisomy were identified, including 9 cases of Trisomy 13, 41 cases of Trisomy 18 and 81 cases of Trisomy 21. Of the 9 Trisomy 13 cases, 1 resulted in live birth. The baby was admitted to the neonatal unit and received palliative care. To determine trends cases of Trisomy 18 and 21 were

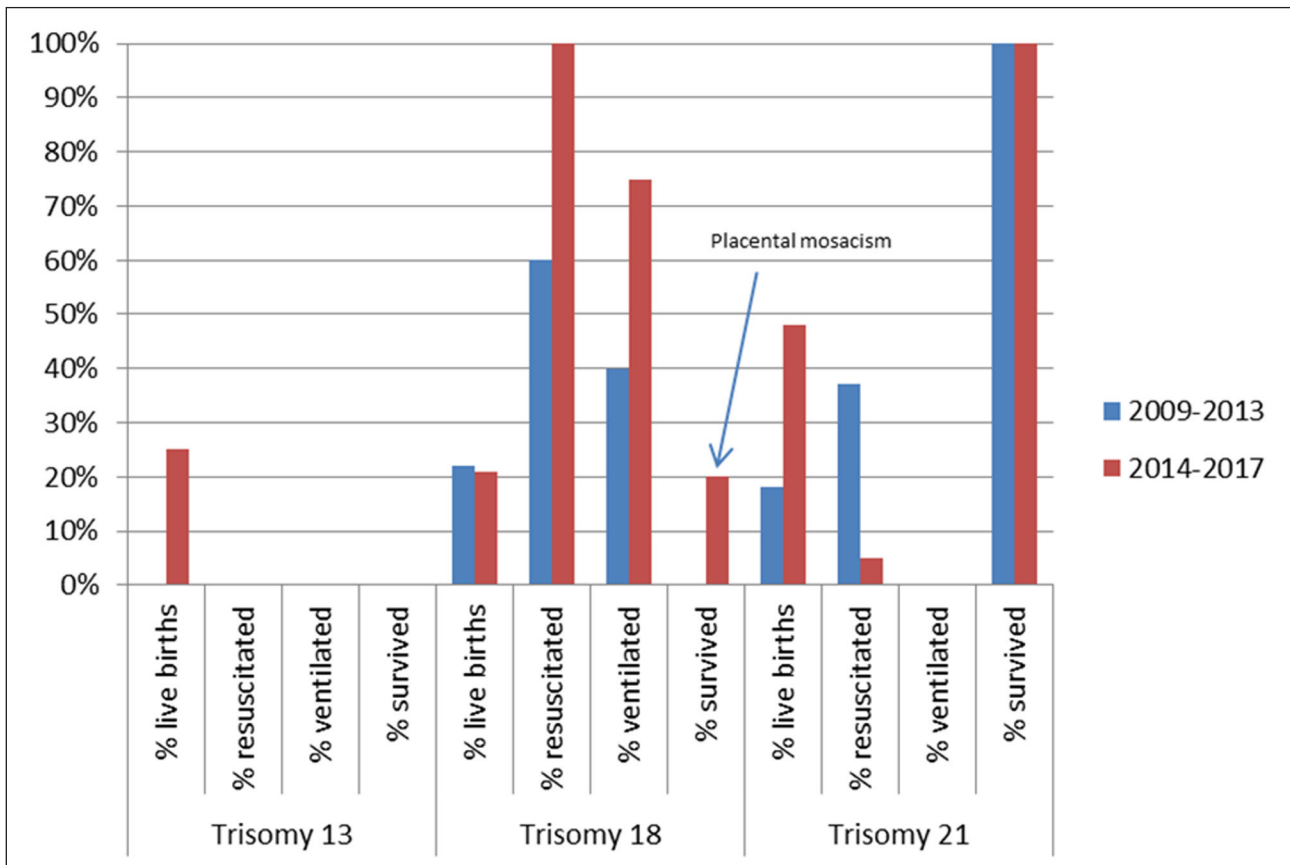


Figure 1 (ABS 4). Trend cases of Trisomy 13, 18 and 21 in the two time periods.

compared over two time periods, 2009-2013 and 2014-2017. 22% of Trisomy 18 cases resulted in live births between 2009-2013 and 21% between 2014-2017. Between 2009-2013, 60% of the Trisomy 18 live births received resuscitation and 40% were ventilated whilst in comparison 100% received resuscitation and 75% were ventilated between 2014-2017. Sadly all neonates with Trisomy 18 died. For Trisomy 21, between 2009-2013 18% cases resulted in live births whilst between 2014-2017 there were 48% live births. No neonates were denied resuscitation, required ventilation. All were admitted and all survived. Results are presented in **Fig. 1**.

CONCLUSIONS

Over a period of time there is a trend of increasing live birth in Trisomy 21. Despite constant live birth rates of Trisomy 18, there has been a 40% increase in those receiving resuscitation and 35% in those receiving ventilation at birth. Considering that all neonates with Trisomy 18 passed away within 2 months of birth, the provision of early compassionate care and balance of parental wishes for intensive care presents an ethical dilemma.

ABS 5

INGEBORG SYLLM-RAPOPORT (1912-2017) – AN EXEMPLARY LIFE FOR CHILDREN AND PAEDIATRICS

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Ingeborg Syllm-Rapoport, the first chair in neonatology in Europe, passed away on March 23. Her biography is an outstanding example of how medical and scientific work has been influenced by social, ideological, and economic frames and boundaries in the 20th century. Herein, we describe Ingeborg Syllm-Rapoport's life and the political and social challenges she had to face living in several countries under different political systems in the 20th century. Born in Cameroon, Ingeborg Syllm-Rapoport was regarded as "Half-Jew" by the Nazi racist law and she was denied her medical doctorate in 1938. She had to wait for almost 80 years until 2015 to undergo the doctoral viva examination at the

age of 102 making her the oldest person in history to receive a doctorate. She went to the U.S. and trained in paediatrics where she met her husband, the biochemist Samuel Mitja Rapoport. Later, during the "McCarthy Era", both were persecuted as communists and had to return to Europe, where they found new employment and became two of the most influential figures at the Charité Hospital in Berlin.

ABS 6

RETROSPECTIVE ANALYSES OF PARENTAL COUNSELING AND DECISION MAKING FOR EXTREME PRETERM BIRTH IN A TERTIARY DUTCH PERINATAL CENTER

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INTRODUCTION

Parents expecting a preterm delivery before 26 weeks of gestation in the Netherlands are actively involved in the decision making about delivery, treatment and support of their child. They receive counseling where they will be assisted in making important decisions concerning the impending delivery and the care of their child. The aim of this study was to get a better understanding of the content and outcome of these consultations and the involved pregnancies.

METHODS

Records of consultations for impending preterm delivery, performed before the gestational age of 26 weeks and between June 2013 and March 2017 in the Erasmus Medical Centre – Sophia Children's Hospital, Rotterdam, the Netherlands, were analyzed and patient databases were used to retrieve pregnancy outcomes. A digital survey was distributed among neonatologist, perinatologists and nurse practitioners. Participants could rate different topics by importance to mention during counseling. A second section of the questionnaire addressed the setting of the consultation and allowed participants to rate how strongly they agreed with statements concerning the setting.

RESULTS

229 parents received a total of 283 consultations. After counseling 78.6% chose active treatment and 19.2% chose comfort care. Of the 179 women of

whom the date of delivery was traceable, 88.2% of the infants received active treatment and 11.8% comfort care. Eventually, 57.5% of the women gave birth after a gestational age of 26 weeks. Topics most often mentioned during consultation were the eventual choices concerning treatment, the choice to do a cesarean section because of fetal condition, and prenatal steroid injections; explanation of the treatment options; long-term problems and disabilities and mortality. The results of our survey show most topics were rated (very) important

to mention during counseling. Topics rated less important to mention concerned technical details of the NICU and using numbers to express mortality rates or using local survival rates when possible.

CONCLUSIONS

This study provided insight in the decisions made around extreme preterm birth and about the outcome of the pregnancies. These results can help clinicians and future parents in their decisions to make. Feedback from parents about the consultations will be needed to further improve our counseling.