

# Selected Abstracts of the 1<sup>st</sup> Congress of joint European Neonatal Societies (jENS 2015) • Session “Ethics and limitations to care”

BUDAPEST (HUNGARY) • SEPTEMBER 16<sup>TH</sup>-20<sup>TH</sup> 2015

## PROGRAMME COMMITTEE

Artúr Beke (Hungarian Society), Morten Breindahl (ESN), Giuseppe Buonocore (UENPS), Pierre Gressens (ESPR), Silke Mader (EFCNI), Manuel Sánchez Luna (UENPS), Miklós Szabó (Hungarian Society of Perinatology), Luc Zimmermann (ESPR)



Supported by



Organizing secretariat



## HOW TO CITE

[Abstract's authors]. [Abstract's title]. In: Selected Abstracts of the 1<sup>st</sup> Congress of joint European Neonatal Societies (jENS 2015); Budapest (Hungary); September 16-20, 2015; Session "Ethics and limitations to care". J Pediatr Neonat Individual Med. 2015;4(2):e040209. doi: 10.7363/040209.

# POSTER PRESENTATIONS

## ABS 1

### METHODS TO DERIVE UTILITIES FOR PEDIATRIC DISABILITY IN A DEVELOPING COUNTRY

E. Spiegel<sup>1</sup>, I. Brajkovic<sup>1</sup>, S. Jondhale<sup>2</sup>, J. Partridge<sup>1</sup>, V. Bhutani<sup>3</sup>, P. Kumar<sup>2</sup>

<sup>1</sup>Pediatric Department, University of California San Francisco, San Francisco, CA, USA

<sup>2</sup>Pediatric Department, Post-Graduate Institute of Medical Education and Research, Chandigarh, India

<sup>3</sup>Pediatric Department, Lucile Packard Children's Hospital, Palo Alto, CA, USA

## INTRODUCTION

Utilities provide preference-based quality-of-life measures for specific disease states. Utilities for neurodevelopmental outcomes of prematurity have been derived in Canada, but have not been conducted in lower-resource countries where disability might be more burdensome.

## PATIENTS AND METHODS

Interviews of mothers and of pediatric providers who care for children at risk for disability in India. We utilized 4 hypothetical cases of multi-attribute disability of varying severity, with added pictograms for ease of understanding. We held 6 focus groups using Standard Gamble (SG) and Time Trade-Off (TTO) methods. They produced equivalent utilities; TTO was easier to understand. We held 6 additional focus groups using a standardized script to train the interviewer. Participants ranked cases as better or worse than death, and decided between a guaranteed fixed lifespan in less desirable health states vs. increasingly shorter lifespans in more desirable health states. Utilities were calculated as the ratio of years of perfect health at the point of indifference to the expected lifespan.

## RESULTS

In focus groups, 100% of participants ranked the 2 severe disabilities as much worse than death, with mean utility scores approaching -1.0. These results are shown in comparison to Saigal et al.'s results, where all 4 cases were viewed as better than death ( $U > 0.0$ ) in Canada (**Tab. 1**). In focus groups, utilities for moderate and severe disability in India were so low that we elected to allow for negative utility states (disability worse than death). Provider interviews took 20-30 minutes; interviews of mothers took 30-60 minutes. Overall, one mother declined focus group participation due to child care constraints. Pictographic characterization of the cases was useful in decision-making.

**Table 1 (ABS 1).** Disabilities in the focus groups in comparison with Saigal et al.'s results.

	Mean Utility Values	
	Focus groups (India)	Saigal et al. (Canada)
<b>Case 1 (mild disability)</b>	0.75	0.74
<b>Case 2 (moderate disability)</b>	0.42	0.56
<b>Case 3 (severe disability)</b>	-0.73	0.23
<b>Case 4 (very severe disability)</b>	-0.82	0.16

## CONCLUSIONS

Focus groups allowed us to select and revise TTO methods. Pictograms of disability outcomes facilitated participant comprehension. Interview time was minimized by using translated documents. Interviews are best conducted by a local interviewer familiar with the language and local societal context. The interviewer became fluent and competent in study methods after a week of training.

# ORAL COMMUNICATIONS

## ABS 2

### UTILITIES FOR DISABILITY IN A DEVELOPING COUNTRY: PROVIDER PERSPECTIVES

S. Jondhale<sup>1</sup>, E. Spiegel<sup>2</sup>, I. Brajkovic<sup>2</sup>, J. Partridge<sup>2</sup>, V. Bhutani<sup>3</sup>, P. Kumar<sup>1</sup>

<sup>1</sup>Pediatrics Department, Post-Graduate Institute of Medical Education and Research, Chandigarh, India

<sup>2</sup>Pediatric Department, University of California San Francisco, San Francisco, CA, USA

<sup>3</sup>Lucile Packard Children's Hospital, Palo Alto, United States

## INTRODUCTION

Utilities provide preference-based quality-of-life measures where a utility value of 1.0 represents perfect health, 0.0 represents death, 0 to 1 a state better than death, and 0 to -1 a state worse than death. Provider utilities for neurodevelopmental disability due to extreme prematurity have been derived in Canada, but have not been derived in lower-resource countries where disability might be more burdensome. We aimed to derive utilities for pediatric neurodevelopmental outcomes in a developing country.

## PATIENTS AND METHODS

Cross-sectional study of 50 nurses and physicians who care for children at risk for disability in India. We derived utilities using 4 hypothetical cases of multi-attribute disability of varying severity and a standardized interview script for Time Trade-Off (TTO) with pictographic depictions of each disability. Participants answered demographic questions, were instructed on TTO, and were allowed to practice until comfortable with TTO. Providers categorized the 4 hypothetical cases as better or worse than death. They chose between a guaranteed fixed lifespan in less desirable health states vs. increasingly shorter lifespans in more desirable health states. Utilities were calculated as the ratio of years of perfect health at the point of indifference to the expected actuarial lifespan.

## RESULTS

Of 35 providers interviewed to date, 69% were female, mean age was 40 (+ 8.7, SD) yrs, 60% were Hindu, and all identified as somewhat or deeply religious. A majority had a child over 2.5

years (80%); none reported having a disabled child. Utility values differed widely across the 4 disability outcomes (**Tab. 1**, shown in comparison to data from Canada).

## CONCLUSIONS

Providers' utilities for pediatric disability are lower in India than in Canada, especially for higher-grade disability. Severe disability is perceived as significantly worse than death in India. This may relate to social stigma, lack of support, limited family and community resources, fewer rights for disabled persons, or a paucity of opportunities for disabled individuals. Further research will elucidate cultural variables affecting utilities for children with disability in differing cultures.

## ABS 3

### LIMITING LIFE SUSTAINING TREATMENT FOR NEWBORN INFANTS: THE WILST STUDY

N. Aladangady<sup>1,2</sup>, C. Shaw<sup>1,3</sup>, K. Gallagher<sup>3</sup>, E. Stokoe<sup>4</sup>, N. Marlow<sup>3</sup> for Collaborator Group

<sup>1</sup>Neonatal Unit, Homerton University Hospital, London, UK

<sup>2</sup>Centre for Paediatrics, Barts and the London School of Medicine and Dentistry, QMUL, London, UK

<sup>3</sup>Institute for Women's Health, University College London, London, UK

<sup>4</sup>Department of Social Sciences, Loughborough University, Loughborough, UK

## INTRODUCTION

Limitation of Life Sustaining Treatment (LST) for newborn infants was first described in 1973. There are no prospective multi-centre studies of the outcomes for babies for whom redirecting Life Sustaining Treatment has been considered.

## AIM

To determine the short-term outcomes of infants for whom clinicians or parents have started discussions

**Table 1 (ABS 2).** Provider utility scores for 4 disability outcomes in India and Canada.

Hypothetical state	Group	Mean (SD)	Mean differences	p-value
Aman/Jamie (minimal impairment)	Indian providers	0.66 (0.43)	-0.14	0.04
	Canadian providers	0.80 (0.25)		
Harish/Chris (mild impairment)	Indian providers	0.16 (0.68)	-0.46	0.0004
	Canadian providers	0.62 (0.36)		
Kuldeep/Pat (severe impairment)	Indian providers	-0.75 (0.28)	-0.70	< 0.00001
	Canadian providers	-0.05 (0.53)		
Manpreet/Sandy (very severe impairment)	Indian providers	-0.59 (0.47)	-0.64	< 0.00001
	Canadian providers	0.05 (0.50)		

about the withholding or withdrawal of LST and/or institution of “do not resuscitate” (DNR) orders.

#### PATIENTS AND METHODS

Utilising a secure on-line database (RedCap), we prospectively collected neonatal unit outcomes (death or discharge home) and care practices for babies for whom limiting LST was considered over one year in 9 hospitals in the North East London Neonatal Network.

The study was funded by a NIHR Programme Development Grant and approved by the East London REC.

#### RESULTS

Data from 88 infants (58 males) were studied; mean gestational age 30.1 (SD: 6.8) weeks, birth weight 1,592 (SD: 1,165) g. Limiting LST was discussed with parents of 67 infants and in 2 cases discussions were only among the clinical team. Limiting LST was first raised by clinicians in 64 cases and by parents in 3 cases; 23 discussions concerned withholding LST, and 47 withdrawing LST.

Following initial discussions, 33 parents (49%) were not in agreement with the clinical team. The parents of 13 infants (27.7%) did not agree for withdrawal of LST. In contrast, of 24 parents specifically asked, all agreed to make a DNR Order.

Fifty infants (56.8%) died following limitation of LST, 25 (28.4%) died receiving full intensive care support, 3 (3.4%) survived despite parents agreeing to limit LST and 10 (11.4%) infants survived following non-agreement to limit LST.

#### CONCLUSIONS

A high proportion of parents do not agree with professional opinion to limit LST for their infants and a proportion of these infants survive. Reasons for non-agreement are being sought as part of our continuing study.

#### ABS 4

### NEONATAL ORGAN DONATION IN SCOTLAND

L. Leven<sup>1</sup>, N. Healy<sup>2</sup>, K. O'Reilly<sup>1</sup>

<sup>1</sup>Royal Hospital for Sick Children, Glasgow, UK

<sup>2</sup>NHS Blood and Transplant, Falkirk, UK

#### INTRODUCTION

Earlier this year, Scotland's first neonatal organ donation occurred at the Royal Hospital for Sick Children in Glasgow, Scotland, UK. Kidneys and liver for hepatocytes were retrieved from a 30 day old infant who died following complications related

to Vein of Galen malformation. Previous studies have estimated that between 6% and 54% of infants dying on neonatal units may be potential organ donors. Following our case a retrospective audit was undertaken to review all neonatal deaths in 2014 in our health board in the West of Scotland to assess if any cases would have met criteria for organ donation.

#### PATIENTS AND METHODS

Neonatal deaths in 2014 were identified through the Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries (MBRRACE-UK) database. Infants > 28 days of life were also included if they were in a neonatal unit at the time of their death. Cases were considered potential organ donors if they met the current acceptance criteria for neonatal donors in the UK; gestation > 34 weeks; weight > 1.6 kg; on a palliative care pathway and normal renal function, as evidenced by normal urine output and creatinine < 100 micromol/litre. In addition, the time to death following extubation or cord clamping was also noted to ascertain whether death occurred within the six hour window that is necessary to allow donation following circulatory death (DCD) to proceed.

#### RESULTS

In total 59 deaths were reviewed. 55 cases were excluded (33/55 due to prematurity). 4/59 (6.8%) cases were considered potential candidates for organ donation. All 4 cases died within six hours of withdrawal of care or cord clamping and therefore could have proceeded to donation.

#### CONCLUSIONS

Neonatal organ donation in the UK is an uncommon event. In our population very few neonates could be considered potential donors and not every family approached would authorise donation. However, with over 400 adults and children on the waiting list for a kidney transplant in the UK, demand for organs is high.

Therefore, when dealing with end of life care, neonatologists should give careful consideration to organ donation.

#### ABS 5

### GLOBAL PREVENTION OF Rh-SENSITIZATION: AN INTERACTIVE, COMMUNITY-CENTERED SOCIAL PLATFORM

A.R. Stark<sup>1</sup>, J.Y. Hall<sup>2</sup>, A. Zipursky<sup>3</sup>, V.K. Bhutani<sup>2</sup>

<sup>1</sup>Department of Pediatrics, Vanderbilt University School of Medicine, Nashville, TN, USA

<sup>2</sup>Stanford University, Stanford, CA, USA

<sup>3</sup>Centre for Global Child Health, Hospital for Sick Children, Toronto, ON, Canada

## INTRODUCTION

In high resource countries, women unaware of their blood type are protected by standard practice whereby those at risk for Rh sensitization receive Rh immunoglobulin in the third trimester and postpartum, or after pregnancy termination. This strategy effectively prevents Rh disease and its neonatal consequences. In contrast, in low resource settings, women at risk for Rh sensitization may be unable to rely on standard implementation of evidence-based prevention strategies, and awareness of their blood type may be more important. Our objective is to develop and test a community-centered model educational program to reduce Rh disease in low resource settings.

## PATIENTS AND METHODS

We will establish 5 model international sites in diverse settings with a high baseline rate of Rh disease. Site leaders will recruit community health workers and local government leaders to serve as regional “champions” who will be trained using a variety of methods to implement Rh prevention programs for pregnant women and

health care workers using a standardized interactive curriculum. Topics will include definition of Rh; Rh sensitization; blood typing and how women can know their blood type; what women should know if they are Rh negative; how and when to get protection from sensitization; tracking one’s reproductive history. Coaching will be used to empower pregnant women to seek blood group typing and receive Rh immunoglobulin postpartum if indicated.

## RESULTS

Metrics for successful implementation of the programs will include increase in rate of blood typing of women in hospitals, community clinics, and homes; increase in rate of identification of Rh negative women in hospitals, community clinics, and homes; appropriate administration of Rh immunoglobulin; reduced rates of Rh sensitization. Data will be collected at baseline and in 3-4 month intervals to analyze potential problems and implement solutions using standard quality improvement methodology.

## CONCLUSIONS

We propose that successful implementation will reduce the rate of Rh sensitization among pregnant women and of neonatal Rh disease. We anticipate that this community based strategy can be readily replicated in other low resource settings.