

PDF hosted at the Radboud Repository of the Radboud University Nijmegen

The following full text is a publisher's version.

For additional information about this publication click this link.

<http://hdl.handle.net/2066/168760>

Please be advised that this information was generated on 2020-09-10 and may be subject to change.

SHORT REPORT

Practices in antenatal counseling for extremely premature infants amongst European trainees

Rosa Geurtzen¹, Arno FJ van Heijst¹, Srinivasarao Babarao², Eleanor Molloy^{3,4}, Jos MT Draaisma¹, and Marije Hogeveen¹

¹Radboudumc Amalia Children's Hospital, Nijmegen, The Netherlands, ²Wirral University Teaching Hospitals, Merseyside, UK, ³Royal College of Surgeons, Dublin, Ireland, and ⁴National Maternity Hospital, Dublin, Ireland

Abstract

There is no international consensus on content and process regarding antenatal counseling in extreme prematurity. The need for adequate training is increasingly recognized. This descriptive study evaluates current practice in antenatal counseling amongst European trainees using an online survey. Focusing on the process, the majority of respondents did not have a medical consensus guideline. Seven percent of the trainees received some formal training. Focusing on the content, about half of the subjects did not mention any statistics about mortality. *Conclusion:* We observed wide variation in actual content and organization in antenatal counseling in Europe amongst European trainees in neonatology.

Keywords

Antenatal counseling, limits of viability, prematurity

History

Received 10 December 2015

Revised 28 January 2016

Accepted 5 February 2016

Published online 7 March 2016

Introduction

The impending delivery of an extremely premature infant confronts prospective parents and professionals with medical, ethical and emotional issues. Parents should be provided accurate and essential information in a comprehensive and understandable way to be able to understand their situation and to participate in the decision-making process. Surveys on practices in antenatal counseling in different regions (e.g. Northern America [1], Asia and Oceania [1] and England [2]) showed heterogeneity in structure and content. A pilot study in a simulated setting exploring antenatal counseling in a Dutch and American cohort, confirmed this variation [3]. Recommendations on antenatal counseling have been made and the need for adequate training to learn this complex task is increasingly recognized [4,5]. It is unsure to what extent formal training for antenatal counseling is already applied in Europe. The practice and perception on prenatal counseling of trainees in neonatology is important; they are our future

neonatologists and it is, for example, known that the site of residency influences their ethos regarding resuscitation and decision-making in extreme prematurity [6]. As part of the participation in the Leonardo da Vinci NOTE (Neonatal Online Training in Europe) project (MH, EM, SB) we used their existing network to explore current practices by trainees in European countries, both in process and content of antenatal counseling in very preterm birth.

Materials and methods

This custom-made online survey focused on both content (mortality, morbidity and practical aspects) and process (organizational aspects and supportive conditions) of antenatal counseling. The questions were about counseling practices prior to any anticipated extreme preterm birth (WHO) and aimed to look at actual practice as experienced by trainees. Information was obtained using an online survey (24 multiple-choice questions), set out in October 2010. Subjects were participants ($n = 190$) from the Leonardo da Vinci NOTE project and were all neonatologists in training. This NOTE project aimed to offer trainees a cross-cultural training program on several neonatal subjects (<http://www.neonatal-training.eu/>). Potential trainees were emailed through national organizations and participation was voluntarily. One reminder was sent in November 2010. Descriptive statistics were used (shown as a percentage, including only responders per question). We analyzed results on an individual level.

Address for correspondence: Marije Hogeveen, Radboudumc Amalia Children's Hospital, Nijmegen, Postal box 9101, huispost 804, 6500 HB Nijmegen, The Netherlands. Tel: +31 243614430. Fax: +31 243614427. E-mail: marije.hogeveen@radboudumc.nl

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

Results

Demographics

The response rate was 27% ($n = 47$). Of those 47 surveys, 43 were completed. Respondents were from 14 countries (Sweden ($n = 10$), United Kingdom ($n = 10$), Denmark ($n = 5$), Estonia ($n = 4$), Spain ($n = 3$), Slovenia ($n = 2$), Germany ($n = 2$), Latvia ($n = 2$), Netherlands ($n = 2$), Norway ($n = 2$), Turkey ($n = 2$), Ireland ($n = 1$), Poland ($n = 1$) and Slovakia ($n = 1$)) and from 38 different hospitals. As background information we refer to Gallagher et al., for a summary of national guidelines on resuscitation at the limits of viability [7].

Process of antenatal counseling

The majority of respondents (64%) did not have a written (local hospital) medical consensus guideline about procedure and/or content of antenatal counseling (Table 1). Forty percent of respondents indicated that counseling conversations were not documented and only verbally communicated to colleagues, whereas 32% was reported in the maternal medical record or in a separate document in maternal (13%) or neonatal (9%) files. Seven percent of all respondents had some formal training in antenatal counseling and the other 93% acquired this knowledge and skill by observing colleagues and doing it themselves. Almost half of the respondents (47%) provided written information to parents; the remaining (53%) did not.

Content of antenatal counseling

Almost all respondents discussed mortality (98%), of whom 55% provided data on mortality based on gestational age and 43% did not discuss numbers or percentages with parents (Table 1). Fifty percent mentioned long-term morbidity data if explicitly requested to do so by the parents and when long-term morbidity data were given in the counseling conversations a variety of sources was used.

Regarding the question “do you elaborate on potential events during delivery?” 81% discussed details of any resuscitation with the parents and also, 66% of the participants discussed that resuscitation may not be successful. There was some uniformity in the discussion of short-term physical problems and therapies related to preterm birth, for example 95% of respondents included the potential need for mechanical ventilation and surfactant 86% covered the need for care in an incubator; 82% the need for umbilical lines and 77% the need for intensive monitoring.

Discussion

European neonatal trainees reported variation in their antenatal counseling practices. Focusing on the process of antenatal counseling we discovered that the majority of respondents did not have a written medical consensus guideline about counselling and the majority did not receive formal training. Also, the counseling conversation was not documented in 40% of the cases and only verbally communicated, a similar percentage as previously found by Janvier et al. studying medical records on antenatal counselling conversations [8].

In our opinion, such an important conversion should be noted - especially when resuscitation decisions are made, and it is important to facilitate fast and easy record keeping.

With regard to the content of antenatal counseling these data suggests that a significant number of respondents (45%) would not mention any statistics relating to mortality. It is questionable whether statistics should be used. Kipnis questions the value of statistics [9] and Boss [10] found that *physicians' predictions of morbidity and death are not central to parental decision-making regarding delivery room resuscitation*. However, Partridge found parents suggesting “more data on outcomes” as an improvement for counseling [1]. Maybe it is best to individually assess whether parents want to hear statistics.

The strongest aspect of this study is being the first study amongst trainees in neonatology in Europe, an interesting equivalent group (assumably little experience in prenatal counseling and a relatively young age). An important limitation of our study is the representativeness since the response rate was low and the convenience sample of subjects makes it impossible to guarantee applicability of our data to all European trainees. Furthermore countries with large differences in population size can have the same number of correspondents. However, we think there is value of this study since it gives insight in current practice and training in different countries from participants of NOTE project. Also it is unknown how counseling is incorporated in the training in different countries. It is unsure whether trainees in neonatology are able to adequately assess all aspects of counseling. Performing adequate antenatal counseling in extreme prematurity is one of the objectives of neonatal trainees; their perception on counseling practices is certainly important.

Variety in reported practice may be due to cross-cultural differences, local policies on care, personal or hospital habits etc., but variation may also be due to insufficient training in antenatal counseling or due the lack of guidance. We believe that variation in antenatal counseling is in the best interest of the patient when the variation is based on individual characteristics for example: different norms and values of parents, different fetal (weight, age, etc.) and maternal characteristics. However, when variation is due to unclear data on morbidity or decision-models, insufficient training, or due to arbitrariness e.g. ‘who’s on call’, then we do not believe that is in the best interest of parents and their expected child. A supported consensus-guideline on antenatal counseling can provide guidance for the professionals who need to perform this complex task: for both senior staff members as well as for trainees. We believe that by providing frames for antenatal counseling, quality will be improved and even more scope for individualization will be created. Besides, it is important to guide trainees in the complex task of performing antenatal counseling. A minority in this survey did receive formal training (7%). This is similar to other findings: only 33% of Canadian fellow programs provide structured training for antenatal counseling at the threshold of viability [5] and 41% of US fellows had no formal training focused on neonatal communication skills [11]. A framework suggested by Moussa et al. might be of help in providing the most appropriate antenatal consultation for parents. Incorporating these kinds of frameworks in an educational curriculum might

Table 1. Process and content of antenatal counseling.

Content of antenatal counseling		n (%)
Organizational aspects		
Do you have any written guideline for antenatal communication?	Yes	10 (21%)
	No	30 (64%)
	Not sure	7 (15%)
Who leads the discussion with the prospective parents?	Consultant (neonatologist)	8 (17%)
	Specialist registrar (senior pediatric/neonatal doctor)	20 (42%)
	Senior house officer (junior pediatric/neonatal doctor)	6 (13%)
	Obstetrician	7 (15%)
	None in specific	6 (13%)
How do you record your communication	Write in maternal notes	15 (32%)
	Fill a separate custom-made document and file it in maternal notes	6 (13%)
	Hold a separate file in neonatal unit with details of all communications	4 (9%)
	No written document – just verbal	19 (40%)
	Any other	3 (6%)
	Have attended formal training in antenatal counseling	3 (7%)
What sort of training do you have in antenatal communication?	No formal training – learned from shadowing seniors and colleagues	40 (93%)
	Just get on with it and talk to parents even though no background experience	0
	Do not need any training to speak to parents	0
	Supportive conditions	
	Do you provide any written information about preterm babies etc.?	Yes
No		23 (53%)
Do you provide information on any support groups or web-based info?	Yes	11 (26%)
	No	32 (74%)
Do you offer the potential parents to visit the neonatal unit before baby's birth? (if feasible)	Yes	39 (91%)
	No	4 (9%)
Content of antenatal counseling		n (%)
Mortality		
Do you discuss issues on mortality?	Provide data on mortality based on gestational age	24 (55%)
	No statistics or numbers mentioned	19 (43%)
	Do not talk about mortality at all	1 (2%)
Do you discuss options of palliative care? (if appropriate)	Yes	38 (88%)
	No	5 (12%)
Morbidity		
How do you discuss long-term neonatal outcome?	Based on local hospital statistics	8 (18%)
	Based on regional network statistics	2 (4%)
	Based on national research study/statistics	6 (14%)
	Based on international trials	6 (14%)
	Do not talk about any statistics unless asked specifically by parents	22 (50%)
	Do you elaborate on potential events during delivery? (<i>more than one option possible</i>)	Need for resuscitation, with details
May not be resuscitable		29 (66%)
Discuss details of airway management, including surfactant administration		29 (66%)
Any other details		12 (27%)
What items of intensive care after birth do you talk about? (<i>more than one option possible</i>)	Need for ventilation and further surfactants	42 (95%)
	Need for umbilical lines	36 (82%)
	Need for intensive monitoring	37 (77%)
	Need for routine ECHO	8 (18%)
	Need for routine cranial ultrasound scans	27 (61%)
	Need for nursing in incubator	38 (86%)
	No specific details given	1 (2%)
	Need for nursing in incubator	38 (86%)
About which potential systemic problems after birth do you talk?	No specific details given	1 (2%)
		25 (57%)

(continued)

Content of antenatal counseling		n (%)
	Nothing specific – mention about overall problems in all systems	
	Talk in detail about every single system including lungs, heart, brain, gut, etc.	13 (30%)
	Do not mention about these before birth of the baby	1 (2%)
	Any other way of discussion	5 (11%)
Practical aspects		
Do you mention/encourage breast-feeding?	Yes	37 (86%)
	No	6 (14%)
Do you discuss need for transfer of the baby to some other hospital? (if situation arises)	Yes	38 (88%)
	No	5 (23%)
Do you discuss financial implications of preterm birth?	Yes	1 (2%)
	No	22 (51%)
	Not applicable in my country	20 (47%)

be a good idea and these trainee curricula may also benefit by the use of simulation [3,4].

Conclusion

We observed wide variation in the actual content and organization in antenatal counseling in European trainees in neonatology.

Acknowledgements

We would like to thank the participants and organization of the Leonardo da Vinci NOTE (Neonatal Online Training in Europe) project for their cooperation.

Declaration of interest

There was no funding. All authors declare that there is no conflict of interest. Informed consent was obtained from all individual participants included in the study.

Compliance with ethical standards

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

References

1. Partridge JC, Martinez AM, Nishida H, et al. International comparison of care for very low birth weight infants: parents' perceptions of counseling and decision-making. *Pediatrics* 2005; 116:e263–71.
2. Duffy D, Reynolds P. Babies born at the threshold of viability: attitudes of paediatric consultants and trainees in South East England. *Acta Paediatr* 2011;100:42–6.
3. Geurtzen R, Hogeveen M, Rajani AK, et al. Using simulation to study difficult clinical issues: prenatal counseling at the threshold of viability across American and Dutch cultures. *Simul Healthc* 2014;9:167–73.
4. Stokes TA, Watson KL, Boss RD. Teaching antenatal counseling skills to neonatal providers. *Semin Perinatol* 2014;38:47–51.
5. Moussa A, Raghavan R, Albersheim SG. Learning the skill of antenatal consultation at the threshold of viability: a framework for trainees. *Ann Pediatr Child Health* 2015;3:1060–7.
6. Janvier A, Barrington K, Deschenes M, et al. Relationship between site of training and residents' attitudes about neonatal resuscitation. *Arch Pediatr Adolesc Med* 2008;162:532–7.
7. Gallagher K, Martin J, Keller M, Marlow N. European variation in decision-making and parental involvement during preterm birth. *Arch Dis Child Fetal Neonatal Ed* 2014;99:F245–9.
8. Janvier A, Barrington KJ. The ethics of neonatal resuscitation at the margins of viability: informed consent and outcomes. *J Pediatr* 2005;147:579–85.
9. Kipnis K. Harm and uncertainty in newborn intensive care. *Theor Med Bioeth* 2007;28:393–412.
10. Boss RD, Hutton N, Sulpar LJ, et al. Values parents apply to decision-making regarding delivery room resuscitation for high-risk newborns. *Pediatrics* 2008;122:583–9.
11. Boss RD, Hutton N, Donohue PK, Arnold RM. Neonatologist training to guide family decision making for critically ill infants. *Arch Pediatr Adolesc Med* 2009;163:783–8.