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A DIFFERENT VIEW – A REPLY

Shared decision-making, value pluralism and the zone of parental discretion

Joseph W. Kaempf (joseph.kaempf@providence.org)[1], Nicholas Kockler[2], Mark W. Tomlinson[1]

1.Women and Children's Program, Providence St. Vincent Medical Center, Portland, OR, USA
2.The Center for Healthcare Ethics, Providence St. Vincent Medical Center, Portland, OR, USA

Correspondence
Joseph W. Kaempf, Providence St. Vincent Medical Center, Women and Children's Program and the Center for Healthcare Ethics, 9205 SW Barnes Road, Portland, OR 97225, USA.
Tel: 503-201-3252 |
Fax: 503-216-7647 |
Email: joseph.kaempf@providence.org

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'Good ethics start with good facts' wrote John Lantos and William Meadow in a 2009 editorial addressing periviability controversies – debates that continue to generate lively discussion amongst neonatologists, obstetricians, ethicists and families (1). How do we best promote shared decision-making with pregnant women who, through no fault of their own, might deliver an extremely premature infant? Unfortunately, the recent '*A Different View*' in this journal by Dr. Patrick Marmion regarding periviability issues in general, and specifically our shared decision-making model at Providence St. Vincent Medical Center (PSVMC) in Portland, OR, is decidedly short on facts and is regrettably inflammatory (2). We appreciate the opportunity to respectfully clarify our bioethical foundation and periviability dialogue framework with the hope of promoting reasoned dialogue and understanding.

The formation of the PSVMC periviability guidelines was a rigorous and multidisciplinary process detailed in three progressive publications, starting with the first explicit, consensus periviability guideline to appear in a peer-reviewed journal (3). Our recent 18-year summary is the largest exposition to date that details the results of a shared decision-making experience at the margins of neonatal survival and good health, an example of value pluralism which makes no claim of ethical superiority, but rather a collaborative attempt at transparency and process improvement (4). Our guidelines were cited by the recent American Academy of Pediatrics Committee on Fetus and Newborn Clinical Report as an exemplary shared decision-making process (5).

Articles in the series A Different View are edited by William Meadow (wlm1@uchicago.edu). We encourage you to offer your own different view either in response to A Different View you do not fully agree with, or on an unrelated topic. Send your article to Dr. Meadow (wlm1@uchicago.edu).

1. Every PSVMC neonatologist, maternal foetal medicine specialist, obstetrician, clinical ethicist, midwife, neonatal nurse practitioner, obstetric and neonatal intensive care unit nurse was invited to participate in our guideline formation. Dr. Marmion has misled *Acta Paediatrica* readers, and he has never worked at PSVMC and is not on staff.
2. PSVMC periviability guidelines do not mandate palliative comfort care at 23 weeks – our group consensus guidelines offer palliative care only at 22 weeks, NICU care at 26 weeks and a shared decision-making process with flexible recommendations at 23, 24 and 25 weeks, see tables 1 and 2 (4). This is entirely consistent with the 2015 clinical recommendations from the American Academy of Pediatrics (5), as well as 2016 guidelines from the American College of Obstetricians and Gynecologists, the 2014 National Institutes of Child Health and Human Development Executive Summary, and the just-published 2017 Canadian Paediatric Society framework from Lemyre and Moore. In addition, our guidelines are wholly within the practice spectrum detailed by Binepal in the 2015 international systematic review of periviability counselling.
3. PSVMC guidelines are not just based upon gestational age; we consistently factor various maternal, foetal and social variables into the multivariable equation that is the nature of true shared decision-making (see Tables 1 and 2, and Methods and Results in reference 4).
4. Our guidelines are not inflexible mandates because any obstetrician, neonatologist or clinical ethicist after considering the entire circumstance with colleagues may give her own considered opinion to a family either in agreement or disagreement with our group consensus guidelines. This transparency and flexibility ensures the integrity of the decision-making process. There is no '*select group*' as Dr. Marmion incorrectly implies.

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Table 1 Providence St. Vincent Medical Center NICU Survival and Neurologic Disability Rates for Extremely Premature Infants born 22 0/7 through 26 6/7 Weeks of Gestation *Updated 3.01.2015*

Gestational Age at Birth (Weeks)	Percentage of infants chosen to be resuscitated For PSVMC exclude Anomalies Inconsistent With Life (AIWL)		PSVMC Inborn Survival Rate for those Infants Resuscitated 1996–2013	Vermont Oxford Network Overall Survival Rate All live born infants 2011–2013	Significant Long-term Neurologic Disability in Survivors Estimated from published analyses
	PSVMC 1996–2013	VON 2011–2013			
22 0/7 to 22 6/7PSVMC N = 54	0%	~30%	0% All 54 palliative care	8%	~50-100%
23 0/7 to 23 6/7 PSVMC N = 80	37%	~80%	21% (6/29) resuscitated) 51 palliative care, 2 AIWL	38%	~40-60%
24 0/7 to 24 6/7 PSVMC N = 109	73%	~95%	59% (47/79 resuscitated) 30 palliative care, 1 AIWL	62%	~30-45%
25 0/7 to 25 6/7 PSVMC N = 157	96%	>98%	78% (115/147 resuscitated) 10 palliative care, 4 AIWL	77%	~25-35%
26 0/7 to 26 6/7 PSVMC N = 206	100%	>99%	87% (176/203 resuscitated) 3 AIWL	84%	~20%

Table 2 Providence St. Vincent Medical Center Obstetric and Neonatology Medical Staff Guidelines for the Care of Extremely Early Gestation Pregnancies and Premature Infants *Updated 3.01.15*

Weeks	Obstetric care	Newborn care
<23 0/7	Tocolysis as indicated. Steroids are not recommended unless NICU care is chosen at 23 weeks. C/Sections are not provided.	Palliative comfort care is provided. Resuscitation and NICU care are not provided because of the extremely high morbidity and mortality.
23 0/7 to 23 6/7	Tocolysis as indicated. Steroids are not recommended unless NICU care is chosen. C/Section for foetal indications should be discussed only if NICU care is chosen. Intermediate obstetric care options are available.*	Palliative comfort care is recommended. Resuscitation and NICU care are not recommended because of the high mortality and the high risk of significant neurologic disabilities in survivors. Resuscitation and NICU care can be provided if the family so chooses.
24 0/7 to 24 6/7	Tocolysis as indicated. Steroids are recommended if the parents have chosen resuscitation and NICU care. C/Section may be declined or chosen after consultation with the medical staff. Caesarean section for foetal indications is recommended only if NICU care is chosen. Intermediate obstetric care options are available.*	Palliative comfort care may be chosen, or resuscitation and NICU care may be chosen after review with the medical staff of the complex morbidity and mortality risks. The medical staff will support either palliative comfort care or NICU care.
Weeks	**Obstetric care**	**Newborn care**
25 0/7 to 25 6/7	Tocolysis as indicated. Steroids are recommended. C/Section is recommended for foetal indications after parental consultation with the medical staff.	Resuscitation and NICU care are recommended as the routine course of action. Palliative comfort care can be provided. *A family request for palliative comfort care will prompt a joint perinatology, neonatology, and clinical ethics consultation to promote clarity, full understanding of the clinical situation, and the relevant ethical issues.*
26 0/7 to 26 6/7	Tocolysis as indicated. Steroids are recommended. C/Section for foetal indications is recommended by the medical staff.	NICU care is provided in virtually all cases unless certain circumstances are present such as major congenital anomalies that are generally incompatible with life at this gestational age.

*Intermediate obstetric management may include foetal monitoring with the use of maternal fluids, oxygen and position changes as needed, but would not necessarily mean Caesarean section. If the foetal heart rate worsens and a nonreassuring foetal status is thought to be significant despite these intermediate measures, then palliative comfort care would be recommended rather than resuscitation and NICU care.

A significant long-term neurologic disability means that a child has a comprehensive IQ <70 (2 or more S.D. below the mean), and/or cerebral palsy, and/or a severe visual or hearing deficit. Some surviving premature infants have two or more of these neurologic impairments, particularly those born at less than 26 weeks. It is important to be aware that about 50% of surviving premature infants who do not have one of the significant neurologic disabilities listed above are reported to have *other neurodevelopmental issues* – a variable mixture of important conditions such as an IQ 70-85, neurobehavioural issues like attention deficit disorder, autism, need for special education or learning disorders, motor and coordination issues, and/or social and behavioural challenges.

Other important factors in addition to the gestational age of the foetus/infant that can affect survival and neurodevelopmental outcomes that we carefully consider during periviability counselling include *estimated foetal weight, sex, singleton vs. multiples, antenatal corticosteroids, the presence of anomalies or birth defects, maternal illnesses and fertility history.*

5. PSVMC periviability decisions are never made inflexibly '*weeks before birth*' because our process encourages updates and discussions with the pregnant woman on an ongoing basis as needed. Adherence to this principle of dynamic clinical change and family preference is a key reason for the quite high positive acceptance of our periviability dialogue (4).
6. It is particularly difficult to understand Dr. Marmion's assertion of a '*hostile workplace*' because he does not work at PSVMC and is not a member of our medical staff; thus, he does not have the ability to assess our local culture nor quality improvement efforts.
7. PSVMC serves a wonderful admixture of Christians, Jews, Hindus, Moslems, nontheists and other faiths, and honours our extraordinary cultural and religious diversity. Fundamental tenets of right and wrong are often context dependent and highly arguable within the multiform society we live. When important values and ethical principles come into conflict within a setting of medical uncertainty and risk, resolution cannot strictly occur by what we think are rational measurements, or hierarchical compulsion. Our foundation of value pluralism recognises that there is no ultimate moral harmony, there are conflicts that have no single right solution, nor foolproof options where harm is never done (6). Tragedy can always result from choice, but this is the very nature of human liberty, and informed family choice is the bedrock of shared decision-making, indeed of a civilised society.
8. Although some follow-up reports suggest health-related quality of life to be similar in extremely premature infants compared to term infants, this is highly contentious because the most recent publications demonstrate that former extremely premature infants rate their health-related quality of life as adults to be significantly poorer than adults born at term (7).
9. Dr. Marmion has stated his personal religious beliefs to us on several occasions, and we respect that as we all do all faiths and cultures. However, he is mistaken to believe he can (or should) enforce his personal faith-based decisions in the setting of medical uncertainty and high technology, cultural diversity and limited evidence based therapies – the very nature of extreme prematurity. Physicians who do not disclose reasonable (and legal) medical care options to families because of religious objections impair patient autonomy (8).
10. Our PSVMC guidelines support a '*zone of parental discretion*', a demarcation that resists infallible fixation by any one person or institution within absolute lower and upper thresholds (9,10). Somewhere between 22 and 26 weeks of gestation is an ethically protected space where families can legitimately make decisions about palliative care versus resuscitation for their infant, and of course with our medical knowledge and compassion to assist. Principles of value pluralism avoid claims of ethical superiority or scientific certainty, because neither exists (4,8–10). Medical protocols that assert there is a best answer to every moral dilemma with no wrong ever done impoverish our ethical life making it simpler and thinner than it actually is (6).

In summary, our PSVMC guidelines are data-driven, consensus-based and transparent, painstakingly updated over years with multidisciplinary input, respectful of variant circumstance and culture, and consistent with international expert recommendations (4,5). Good ethics does indeed start with good facts, but should proceed to civility and rationality, that is the ability to discuss any topic be it religion, science, art or politics in such fashion that refrains from dogmatism, misrepresentation and righteous indignation and then rightfully proceeds to shared decision-making and family preference.

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CONFLICT OF INTEREST
The authors declare no conflict of interest with any competing financial interest, funding or commercial product related to this manuscript.

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