

CPS position statement for prenatal counselling before a premature birth: Simple rules for complicated decisions

Annie Janvier MD PhD FRCPC¹, Keith J Barrington MB ChB², Khalid Aziz MA MEd(IT) FRCPC FAAP³, Eduardo Bancalari MD⁴, Daniel Batton MD⁵, Carlo Bellieni MD⁶, Brahim Bensouda MD⁷, Carlos Blanco MD PhD FRCPI⁸, Po-Yin Cheung MBBS PhD FRCPC⁹, Felicia Cohn PhD¹⁰, Thierry Daboval MD FRCPC FAAP MSc¹¹, Peter Davis MD FRACP¹², Eugene Dempsey ChB¹³, Amélie Dupont-Thibodeau MD PhD(c)¹⁴, Emanuela Ferretti MD FRCPC¹⁵, Barbara Farlow BEng MBA¹⁶, Matteo Fontana MD¹⁷, Etienne Fortin-Pellerin MD¹⁸, Aviva Goldberg MD MA¹⁹, Thor Willy Ruud Hansen MD PhD MHA FAAP²⁰, Marlyse Haward MD²¹, Lajos Kovacs MD FRCPC FAAP²², Anie Lapointe MD FRCPC²³, John Lantos MD²⁴, Colin Morley MD²⁵, Ahmed Moussa MD²⁶, Gabriel Musante MD MSc²⁷, Sophie Nadeau MD²⁸, Colm PF O'Donnell MB MRCP MRCPCH FRACP FJFICMI PhD²⁹, Kristina Orfali PhD³⁰, Antoine Payot MD PhD³¹, C Anthony Ryan MB ChB³², Guilherme Sant'Anna MD PhD³³, Ola D Saugstad MD PhD FRCPE³⁴, Sadath Sayeed JD MD³⁵, Theophil A Stokes MD³⁶, Eduard Verhagen MD PhD JD³⁷

In 2007, the Fetus and Newborn Committee of the Canadian Paediatric Society indicated that the 1994 position statement 'Management of the woman with threatened birth of an infant of extremely low gestational age' (1) needed revision. During a collegial process, which included an extensive review of the literature on the subject, the following important points were made:

- Gestational age (GA) estimates are inaccurate and, therefore, cannot be used as though they are precise to make life and death recommendations.
- Estimates of GA should not be used alone but should be used in conjunction with other prognostic indicators.
- Any position statement should emphasize communication and how to interact with parents, focusing on how to personalize antenatal consultation, shared decision making and ensuring that the life trajectory of the child (both at birth and in the neonatal intensive care unit [NICU]) is optimized.
- Information shared with parents, in addition to estimates of survival and long- and short-term morbidity, should include

evidence about quality of life, and the experience of parents and children in and after the NICU.

In October 2012, a new position statement, 'Counselling and management for anticipated extremely preterm birth' (2), was published by the Canadian Paediatric Society, which we found to be extremely disappointing because it did not incorporate many of the above points. Since 1994, our knowledge regarding both the survival rates of extremely preterm infants (3-5) and the quality of life of those survivors has substantially improved (6-13). We have also learned more about what parents want to know when they are facing the delivery of an extremely premature infant (14-16), as well as their experiences in the NICU (17) and the impact on families in the long term (18,19). Disturbingly, we have also learned that preterm infants are routinely denied life-sustaining treatment, even when their prognosis is better than that of other patients who routinely receive such treatment (2,20-28). None of this evidence was included in the new statement.

The statement supposes that all of the medical staff involved with these decisions need to be given simple rules (21). We reject

¹Pediatrics and clinical ethics, Université de Montréal and Centre Hospitalier Universitaire (CHU) Sainte-Justine; ²Pediatrics, Université de Montréal, Montreal, Quebec; ³Pediatrics, University of Alberta, Royal Alexandra Hospital Neonatal Intensive Care Unit, Edmonton, Alberta; ⁴Pediatrics, Obstetrics and Gynecology, University of Miami, Division of Neonatology, University of Miami Health System, Miami, Florida; ⁵Neonatology, Southern Illinois University School of Medicine, Carbondale, Illinois, USA; ⁶Neonatal Intensive Care, Siena University Hospital, Siena, Italy and the Bioethical Committee of the Italian Pediatric Society; ⁷Pediatrics, McGill University, Montreal, Quebec; ⁸Pediatrics, National Maternity Hospital Dublin, National Children's Research Centre, Our Lady's Children's Hospital, Dublin, Ireland; ⁹Departments of Pediatrics, Pharmacology and Surgery, University of Alberta, Edmonton, Alberta; ¹⁰University of California, Irvine, Kaiser Permanente Orange County, California, and American Society for Bioethics, USA; ¹¹University of Ottawa, Children Hospital of Eastern Ontario, Ottawa, Ontario; ¹²Neonatal Medicine, Royal Women's Hospital, Victoria, Australia; ¹³Cork University Maternity Hospital and Department of Paediatrics & Child Health, University College Cork, Cork, Ireland; ¹⁴CHU Sainte-Justine, Montreal, Quebec; ¹⁵Pediatrics, University of Ottawa, The Ottawa Hospital/Children's Hospital of Eastern Ontario, Ottawa, Ontario; ¹⁶The DeVeber for Bioethics and Social Research, Patients for Patients' Safety Canada; ¹⁷Neonatal and Pediatric Intensive Care Unit, Children's Hospital of Lucerne, Lucerne, Switzerland; ¹⁸Pediatrics, Université de Sherbrooke, CHU de Sherbrooke, Sherbrooke, Québec; ¹⁹Department of Pediatrics and Child Health, University of Manitoba e-Health Services, Winnipeg, Manitoba; ²⁰Oslo University, Oslo, Norway; ²¹Albert Einstein College of Medicine, Children's Hospital at Montefiore, Bronx, New York, USA, Montefiore-Einstein Bioethics Committee; ²²Pediatrics, McGill University, Jewish General Hospital; ²³CHU Sainte-Justine, Montreal, Quebec; ²⁴Children's Mercy Bioethics Center, Children's Mercy Hospital, Kansas City, Kansas, USA; ²⁵Neonatal Medicine, Royal Women's and Royal Children's Hospitals, Melbourne, Australia; ²⁶Pediatrics, CHU Sainte-Justine, Montreal, Quebec; ²⁷Newborn Services, Maternal & Child Department, Hospital Universitario Austral, Pilar, Argentina; ²⁸Pediatrics, Université Laval, CHU de l'Université Laval, Québec, Québec; ²⁹Pediatrics, University College Dublin, The National Maternity Hospital, National Children's Research Centre, Dublin, Ireland; ³⁰Bioethics in Pediatrics, Columbia University, New York, New York, USA; ³¹Pediatrics and clinical ethics, University of Montreal, CHU Sainte-Justine; ³²Pediatrics, Cork University, Cork, Ireland; ³³Pediatrics, McGill University, Montreal, Quebec; ³⁴Pediatrics, Oslo University Hospital, University of Oslo, Oslo, Norway; ³⁵Global Health and Social Medicine and Pediatrics, Harvard Medical School, Boston Children's Hospital, Boston, Massachusetts; ³⁶Pediatrics, Walter Reed National Military Medical Center, Uniformed Services University of the Health Sciences, Bethesda, Maryland, USA; ³⁷Pediatrics, Neonatologist, Director of Pediatrics, University Medical Center Groningen, Groningen, Netherlands

Correspondence: Dr Keith J Barrington, Pediatrics, Université de Montréal, 3175 chemin Côte-Sainte-Catherine, Montreal, Quebec H3T 1C5.

Telephone 514-345-4931 ext 5929, fax 514-345-4822, e-mail keith.barrington@umontreal.ca

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this premise. When decisions are complicated, decision making must be nuanced. There is no other clinical situation in which doctors avoid responsibility for life-and-death decisions by proposing and following simple and scientifically flawed algorithms (21). We are concerned that several recommendations are unsupported by any of the literature that was cited. We are also concerned about the lack of an explicit ethical underpinning for the recommendations.

In our opinion, the limitations of the 2012 policy statement are as follows:

- The recommendations for intervention thresholds, based on completed weeks of gestation (which are inaccurate), are not rational. There is no discussion of how these particular thresholds were chosen compared with other possible thresholds.
- The literature review is incomplete, with significant gaps. It should be systematic and the criteria for selecting different references explicit. There are several large population-based cohort studies that are not referenced (29), whereas others are included, but not their latest published data (30). A database study showing a very small increase in mortality between one and five years of age among extremely preterm infants is quoted (31), with no indication of why this reference was chosen over many hundreds of other potential studies.
- There is scarce acknowledgement of the importance of quality of life, and no recognition of the data showing that quality of life is not related to GA (12).
- There are significant errors in several quotations of the literature. For example, all of the values in Table 2 are incorrect; also, the proportions of children from the Epicure study with severely abnormal outcome and from the Australian cohort are incorrectly quoted.
- Different long-term outcome measures are treated as though they were equivalent. One of the studies referenced for Table 2 included all grades of cerebral palsy as severe disability, while another only included 'severe' cerebral palsy; one study included infants with a two-year Bayley Mental Development Index (MDI) >2 SDs below the mean, while another only if the MDI was >3 SDs below the mean.
- The definitions of severe disability are not appropriate; a low Bayley MDI score at two years of age is not a disability, and many infants with low two-year scores experience no disability in the long term. If followed and evaluated for their cognitive function later in life, there is no difference between infants of GAs between 23 and 26 weeks.
- The Grading of Recommendations Assessment, Development and Evaluation (GRADE) system requires an explicit systematic review of all of the evidence, the construction of 'summary of findings tables', an exhaustive process of rating the quality of the evidence and, finally, the creation of recommendations (32). Most of these steps were omitted; only the terms for strong or weak recommendation are used, which is defined by the GRADE working group as "the extent to which one can be confident that the desirable effects of an intervention outweigh its undesirable effects" (33); such a distinction is meaningless without performing all of the previous steps, and is not relevant to ethical decision making concerning life-sustaining interventions.

A WAY FORWARD

We have learned enough about decisions for extremely premature babies that simple guidelines are no longer needed. Decisions in the perinatal period should be made in a manner similar to decisions for any other patient. All health care providers should be adequately educated in ethical decision making and

in communicating with families. In very high-risk situations, both before and after birth, when dealing with incompetent babies and young infants, the ethical principles are very similar. A statement to help doctors in these situations should ideally have the following characteristics:

- Explain that decision making should be personalized in terms of communication style, information needs and decision-making style of the parents in the best interest of their child.
- Recommend that all patients are considered individually, and that care is family-centred and personalized.
- Acknowledge that transfer to a tertiary care centre and administration of antenatal steroids do not mandate either institution of life-sustaining interventions or an operative delivery by Cesarean section.
- State that infants born at extremely low GAs have a reduced survival and increased risks of adverse long-term outcomes, but that survivors generally have a good quality of life.
- Explain that decision making for the extremely preterm infant should be an ongoing dialogue with parents, and that if new information becomes available, especially at the time of birth, decisions should be re-evaluated.
- Encourage caregivers to share information that includes the quality of life, and the life experiences of preterm infants and their families both during and after their NICU stay. This information should be balanced and include what some children cannot do because of disabilities, but also what they and their families can do.
- Discuss the timing of death. The average age at death of neonates who die in the NICU has been increasing. The consequences of intensive care before death should be accounted for in ethical considerations. Re-evaluation of the appropriateness of life-sustaining interventions during the NICU stay to reduce the burdens of care is at least as important for this group of patients as the initial decision to actively intervene.
- Recognize the limitations of 'disability categorization'. For preterm infants, some disabilities that are labelled 'minor' in the medical literature, such as behavioural problems, may be considerably more difficult for some families to cope with than 'severe' disabilities, such as correctable deafness or ambulant cerebral palsy. The categorization of some impairments as major (eg, cerebral palsy) and others as minor (eg, behavioural problems) by health care practitioners has implied value judgements that may not be shared by families.
- Avoid conflating death and disability. Guidelines and 'calculators' for decision making tend to conflate survival and disability (2,34). Survival and disability do not have the same meaning for families. Quantifying 'survival without disability' to make a single dichotomous outcome helps the design of research projects, but conflating them in the clinical setting should be avoided because it sends an ambiguous and unclear message. Parents should be informed of the possibility of survival and disabilities separately.
- Mention adaptation and coping of families: The meaning of disability (and not just the risks of disabilities) and the impact on families should be included in the discussions.

CONCLUSION

There is no easy way to make decisions regarding life and death. However, guidelines for such decisions should at least start with accurate facts. Classifying infants according to inaccurate estimates of completed seven-day periods of GA is inappropriate because it ignores facts about the inaccuracy of GA assessments or the range of outcomes within each GA strata (21). It also sets arbitrary limits on parental participation in shared decision making by framing the

decisions that are offered to them based on these inaccurate conclusions drawn from meaningless GA categories.

Information related to survival and outcomes, including quality of life, should be personalized, following an analysis of the risks for a particular infant and taking into account all of the relevant medical characteristics. A shared decision must then incorporate and be consistent with the values and desires of the parents and the best interest of their child. The limitations of the evidence should be an incentive to examine each case in a personalized fashion (35). Given our wide range of uncertainties about any baby in the first hours of life, the morally appropriate approach is to establish individualized goals of care with each family for each baby.

Finally, a position statement proposing recommendations for withholding or withdrawing life sustaining interventions should be explicit about what criteria have been used to make those recommendations. Are these criteria based on a low survival rate? If yes, what is considered to be too low a survival? Are they based on the

burden of interventions? If yes, then state which interventions, and how the burden is to be evaluated and by whom? If the criteria are based on the likelihood of survival with unacceptable outcomes, then state what outcomes are considered to be worse than death, and why, and to whom?

The Canadian Paediatric Society is an important and respected body that has done much to promote the health and well-being of Canadian children, and its statements have influence around the world. Unfortunately this position statement does not reflect best practice in ethical decision making regarding very high-risk deliveries. It is based on premises that may prejudice the outcomes of extremely preterm birth and limit the scope of ethical decision making in individual cases. The authors of this commentary respectfully request that this position statement be withdrawn, or revised based on input from the wider neonatal community and from parents, and that the Canadian Paediatric Society continues to fulfill its mission to advocate for all children, including preterm infants.

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Counselling and management for anticipated extremely preterm birth

Ann L Jefferies MD Med FRCPC¹, Haresh Kirpalani MB MSc MRCP FRCPC²,
Susan G Albersheim MD PhD FRCPC³, Andrew Lynk MD⁴

We thank the editors of *Paediatrics & Child Health* for the opportunity to respond to the commentary by Janvier, Barrington and their 35 coauthors (1) regarding the Canadian Paediatric Society (CPS) position statement 'Counselling and management for anticipated extremely preterm birth' (2). Janvier et al express several concerns, the primary being that the statement provides "simple rules" for counselling and decision making regarding anticipated extremely preterm birth, rules that are based on gestational age (GA). They also raise issues of process.

In developing this statement, a detailed review of the literature describing the management and outcome of extremely preterm birth, antenatal counselling and models of decision making was undertaken. All studies were reviewed, with a focus on more recent cohorts and population-based studies rather than reports restricted to tertiary centres. This was because it is often community practitioners who initially manage the imminent birth of an extremely preterm infant, a particularly important consideration in the context of Canadian geography. The Fetus and Newborn Committee (FNC) also considered contemporaneous issues during statement development, including uncertainty among health care providers regarding the management of extremely preterm birth and existing recommendations that infants born at 22, 23 and even 24 weeks' gestation should not be resuscitated (3). The FNC was aware that both tertiary and primary care practitioners were requesting guidance regarding management of extremely preterm birth, particularly practitioners in the community faced with the difficult situation of caring for women at risk for extremely preterm birth.

The statement was discussed at three meetings of the Neonatal-Perinatal Section of the CPS. An overview of the nearly completed statement, including data tables and recommendations, was presented to section members. Following approval by the FNC, including representatives from the Society of Obstetricians and Gynecologists of Canada, College of Family Physicians of Canada and the Canadian Association of Neonatal Nurses, the statement was extensively reviewed and approved by the CPS Bioethics Committee (membership included two neonatologists), CPS Community Paediatrics Committee, Society of Obstetricians and Gynecologists of Canada and the CPS Board of Directors.

The substantive question is: Should GA be used for counselling and decision making? Parents facing health decisions regarding their children, including the anticipated birth of a preterm infant, want information about their infant's outcome (4-7). It is difficult, if not impossible, to separate GA and prognosis, with GA being the strongest single predictor of outcome (8). The prognosis for a baby born at an estimated GA of 22 weeks differs significantly from that of a baby born at an estimated GA of 26 weeks, particularly in

terms of survival. Wilkinson (9) argues that GA-based guidelines are often still the best way of providing structure for individuals involved in perinatal decision making and for supporting both parents and clinicians facing extremely difficult choices. Lantos (10) acknowledges that if GA is used as a measure of illness severity and an indicator of survival, it is "as uncontroversial as other measures of illness severity". The universally funded Canadian system of antenatal care emphasizes early screening and prevention of complications; hence, for many women in Canada, GA is known with a considerable degree of accuracy through the use of early ultrasonography, shown to be accurate to within five days (11). Fetal sex and estimated weight may be uncertain when women present in preterm labour.

It is important to consider how the CPS statement uses GA as a basis for recommendations. At the time of statement development, the literature indicated that overall survival of infants born at 22 weeks' GA was approximately 5% and, therefore, a noninterventional approach was recommended. This is articulated in both the statement body and recommendations. For infants >22 completed weeks' GA, an approach to discussion of the outcomes and to decision making that is individualized for each infant and family is recommended, with discussion of factors in addition to GA (eg, birthweight, multiplicity) that contribute to prognosis included in the body. Recognizing that some guidelines (and perhaps some physicians) did not advocate active management of infants born at 22, 23 and even 24 weeks' GA, recommendation 12 provides affirmation for families and clinicians that active management is, in fact, an appropriate choice. The statement also recognizes that GA may not always be certain.

Previous work by Janvier et al (12-15), using predominantly survey methodology, has raised ethical concerns that extremely preterm infants may be regarded differently than older infants and children who have a similar risk of mortality from neurological sequelae with respect to initiation of life-sustaining therapies. The CPS Board does acknowledge this concern and will refer this important issue to our Bioethics Committee for assessment, consultation and recommendation.

Janvier et al (1) describe an approach to decision making for high-risk infants that is, in fact, very similar to that of the statement. A considerable portion of the statement, as well as one-half of the recommendations, deals with counselling and decision making. The statement emphasizes shared decision making, going further than Chance was able to do in the previous CPS statement (16). The importance of understanding parental values and experiences, helping parents understand their own values, avoiding personal bias, engaging parents in shared decision making, and ongoing dialogue and re-evaluation of care plans before and after

¹Department of Paediatrics, University of Toronto, Mount Sinai Hospital, Toronto, Ontario; ²Department of Paediatrics, University of Pennsylvania, Philadelphia, Pennsylvania, USA; ³Department of Paediatrics, University of British Columbia, Children's and Women's Hospitals of British Columbia, Vancouver, British Columbia; ⁴President, Canadian Paediatric Society, Ottawa, Ontario
Correspondence: Dr Ann L Jefferies, Department of Paediatrics, University of Toronto, Mount Sinai Hospital, Room 775, 600 University Avenue, Toronto, Ontario M5G 1X5. Telephone 416-586-8295, fax 416-586-8745, e-mail ajefferies@mtsina.on.ca
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birth are all discussed. We agree that discussion with parents may include balanced information about quality of life and experiences of families with children with disabilities, as well as information about survival and outcomes. As more evidence regarding quality of life of survivors of extreme prematurity becomes available, it will continue to be used to inform decision making for these infants. Establishing individualized goals of care with families, in the best interests of their child, is a reasonable approach.

Janvier et al (1) state that there are errors in the statement. The EPIPAGE study (17) as well as the most current publication of the EPICure study (18) at the time of statement development were referenced. The EPICure data are correctly quoted. The values in Table 2 are correct; however, the percentages in the Jacobs (19) and Synnes (20) studies refer to survival free of impairment whereas those for the Robertson study (21) refer to survival free of major impairment, as Janvier et al point out. The statement provides the definition of 'major adverse neurodevelopmental out-

come' that is used in many follow-up studies and uses the word 'disability' as cited in much of the literature (22). The Grading of Recommendations Assessment, Development and Evaluation (GRADE) system was used to nuance the recommendations because it separates quality of evidence and strength of recommendations, recognizes variability in values and preferences, and considers resource use to some extent. Limitations on statement length precluded description of specific methodology.

The Janvier et al (1) commentary identifies important considerations in the process of decision making. The CPS position statement also provides a framework for practitioners faced with the imminent birth of an extremely preterm infant.

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