

Counselling and management for anticipated extremely preterm birth

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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

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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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