Attitudes of Canadian Neonatologists in Delivery Room Resuscitation of Newborns at Threshold of Viability

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Abstract

Objective: There is great debate regarding the extent of intensive care interventions for extremely premature newborns. In this report, we describe Canadian neonatologists' attitudes towards delivery room resuscitation decisions in neonates at the threshold of viability.

Methods: We interviewed neonatologists (N = 121) practising in Canadian tertiary care neonatal units between June 2004 and April 2005, and asked whether they would support a parental request not to initiate resuscitation for newborns of 23 to 26 weeks' gestation. Bivariate analyses were performed to identify sociodemographic or cultural factors that might affect resuscitation decisions.

Results: Most Canadian neonatologists would support a parental request not to initiate resuscitation of an infant at 23 and 24 weeks' gestation (98% and 80%, respectively). However, we observed heterogeneity across the country in attitudes primarily at 25 weeks, but also at 24 weeks' gestation. At 24 weeks' gestation, decisions also appear to be significantly related to personal experience with a disabled close friend or relative. For newborns of 25 weeks' gestation, neonatologists are divided: a majority (76%) would strongly advocate resuscitation and/or resuscitate a "viable" fetus against parental wishes, and a minority (24%) would agree not to initiate treatment. At 26 weeks' gestation, more than 97% would not support a request not to initiate resuscitation.

Conclusion: Attitudes of Canadian neonatologists towards resuscitation of newborns at the threshold of viability primarily differ at 25 weeks and to a lesser extent at 24 weeks of gestation. Our findings highlight important nuances in relation to existing national guidelines.

Key Words: Neonatal care, decisions, resuscitation, newborn, premature, extremely low birth weight infant

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Résumé

Objectif : La portée des interventions de soins intensifs offertes aux nouveau-nés extrêmement prématurés suscite de grands débats. Dans le cadre de ce rapport, nous décrivons les attitudes des néonatologistes canadiens envers les décisions liées à la réanimation des nouveau-nés au seuil de la viabilité en salle d'accouchement.

Méthodes : Entre juin 2004 et avril 2005, nous avons interviewé des néonatologistes (N = 121) œuvrant au sein d'unités néonatales de soins tertiaires au Canada et leur avons demandé de nous faire part de la façon dont il traitait les demandes parentales, en ce qui a trait au fait de ne pas entamer des manœuvres de réanimation pour les nouveau-nés issus d'une gestation allant de 23 à 26 semaines. Des analyses bidimensionnelles ont été effectuées pour identifier les facteurs sociodémographiques ou culturels qui pourraient affecter les décisions quant à la réanimation.

Résultats : La plupart de néonatologistes canadiens ont affirmé qu'ils soutiendraient une demande parentale visant à ne pas entamer des manœuvres de réanimation pour les nouveau-nés issus d'une gestation de 23 semaines et de 24 semaines (98 % et 80 %, respectivement). Cependant, nous avons constaté une certaine hétérogénéité des attitudes partout au pays, principalement dans le cas des nouveau-nés issus d'une gestation de 25 semaines, mais également dans celui des nouveau-nés issus d'une gestation de 24 semaines. En ce qui concerne ces derniers, les décisions semblent aussi significativement associées à l'expérience personnelle liée à un ami ou à un proche handicapé. Dans le cas des nouveau-nés issus d'une gestation de 25 semaines, les néonatologistes sont divisés : la majorité d'entre eux (76 %) plaideraient fortement en faveur de la réanimation et/ou réanimeraient un fœtus « viable » à l'encontre des souhaits des parents, et une minorité (24 %) consentiraient à ne pas entamer de traitement. Dans le cas des nouveau-nés issus d'une gestation de 26 semaines, plus de 97 % des néonatologistes ne soutiendraient pas une demande visant à ne pas entamer des manœuvres de réanimation.

Conclusion : Les attitudes des néonatologistes canadiens envers la réanimation des nouveau-nés au seuil de la viabilité divergent principalement dans le cas des nouveau-nés issus d'une gestation de 25 semaines et, dans une moindre mesure, dans celui des nouveau-nés issus d'une gestation de 24 semaines. Nos résultats soulignent les nuances importantes en ce qui a trait aux directives cliniques nationales existantes.

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INTRODUCTION

The process of decision making regarding resuscitation of newborns at the threshold of viability continues to be the subject of intense debate. Medical advances, such as the use of antenatal steroids and surfactant therapy, have resulted in increased survival of extremely premature babies without a comparable improvement in neonatal morbidity.[1] The literature defines the lower limit of viability as between 22 and 24 weeks' gestation.[2,3] Overall, newborns at or below 26 weeks' gestation represent less than 0.2 % of all live births but proportionately carry the greatest burden of long-term disabilities.[4–6] Newborns at or below 24 weeks' gestation generally have less than a 50% chance of intact survival.[4,5]

Despite an explosion of long-term neonatal outcome data to assist physicians in neonatal care decisions,[7] practices in perinatal centres internationally continue to differ markedly for newborns of 22 to 25 weeks' gestation.[8] In 1994, in an effort to guide practice across Canadian tertiary care perinatal centres, the Maternal-Fetal Medicine Committee of the Society of Obstetricians and Gynaecologists of Canada and Fetus and Newborn Committee of the Canadian Paediatric Society jointly published a statement regarding the management of women facing the probable birth of an extremely premature infant.[4] These guidelines (summarized in Table 1) were defined by expert committees and reviewed by physicians involved in the care of these newborns. They were based mostly on available survival and long-term neurological outcome data at the time. There has been no study done to determine whether these guidelines actually reflect practices of Canadian physicians, and these guidelines require updating. In this study, we surveyed Canadian neonatologists' attitudes regarding delivery room resuscitation decisions for newborns at the threshold of viability.

METHODS

Cohort and Data Collection

All neonatologists practising in tertiary care neonatal units in Canada (N = 169) between June 2004 and April 2005 were asked to participate in a telephone interview about attitudes of neonatologists towards delivery room decisions at the threshold of viability. Names were obtained from the Canadian Neonatal Network Database and from telephone communication with all tertiary care neonatal intensive care units in Canada. Interviews were conducted for durations of 20 to 30 minutes, in either English or French. The questionnaire (available on request), developed in our institution, was initially tested with neonatologists from our own institution; no major modifications were made after the pilot test. The questionnaire was sent to Canadian neonatologists in advance of the interview. In the first part of the survey, neonatologists were asked closed-ended questions about social and cultural demographics. The following questions were asked: age, gender, ethnic background (respondents were given a list of options; data are summarized in Table 2), country of medical and neonatal fellowship training (categorized as Canada or other), and number of years of practice as a neonatologist. Respondents were also asked whether they had children, whether they had personal experience with a close friend or relative with a disability (they were asked whether they personally knew anyone with a physical "handicap," who required a wheelchair, crutches, or other physical help, or with a mental "handicap," who required special schooling or care), and the percentage of their work time spent in the practice of neonatology. Involvement in neonatal follow-up, as defined by more than a 50% clinical practice time commitment to follow-up, was determined by contacting the neonatal follow-up clinic directors of each of the tertiary care centres in Canada. In the second part, neonatologists were asked open-ended questions on their attitude towards scenarios in which parents requested withholding resuscitation at birth for a baby at 23, 24, 25, or 26 weeks' gestation (Appendix). The number of weeks of gestation was further detailed as the number of completed weeks (i.e., 23 weeks and 0 days to 23 weeks and 6 days of gestation were all referred to as 23 weeks' gestation) and was based on current gestational age determination standards (first day of last menstrual period if cycle dates were accurate or early ultrasound dating). The study protocol was approved by the University of British Columbia's Behavioural Research Ethics Board and the Children's and Women's Health Centre of British Columbia's Research Ethics Board.

Data Categorization

The responses from each participant (N = 121) to the different scenarios (23, 24, 25, or 26 weeks' gestational age) were independently reviewed and categorized by three investigators (two neonatologists and a research assistant not professionally involved in newborn care) according to the level of constraint applied to respect of a parental request not to initiate intensive care. Data were categorized as *no constraint* (0) if they would agree not to initiate intensive care without reserve, *minimal constraint* (1) if they would agree after ascertaining that the parents were fully informed

ABBREVIATIONS

ANOVA	analysis of variance
CPS	Canadian Paediatric Society

Table 1. Summary of the SOGC–CPS guidelines for initiation of neonatal intensive care at threshold of viability[4]

Gestational age	Recommendation (completed weeks)*
Less than 22 weeks	Non-viable. Provide compassionate care only.
22 weeks	Rarely viable. Provide compassionate palliative care, active treatment only at the request of fully informed parents.
23 to 24 weeks	Survival rates increase from 10–50%, with 20–35% disability. Resuscitation decisions based on parents' wishes, with flexibility based on condition of baby at birth.
25 to 26 weeks	Survival rates 50–80%, with 10–25% disability. Recommend active resuscitation.

*Completed weeks = number of weeks of gestation; e.g., 22 weeks = 22 $^{+0}$ to 22 $^{+6}$ days.

and competent to make the decision (e.g., additional follow-up antenatal consult visits, or second physician involvement), *moderate constraint* (2) if they would strongly disagree and try to convince parents to allow resuscitation, and *strong constraint* (3) if they would resuscitate against parental wishes or obtain a court order to resuscitate.

Statistical Analysis

Data validation was performed for each of the different scenarios using kappa statistics to determine the degree of agreement between each combination of two investigators. In order to examine the relationships between the social and cultural characteristics of respondents and the level of constraint imposed at each gestational age, bivariate analysis was performed using raw (0, 1, 2 or 3) or condensed (minimal to no constraints [0 and 1 combined], moderate to strong constraints [2 and 3 combined]) levels of constraint. For continuous variables, differences in means were determined using a *t* test or ANOVA test. For categorical variables, differences in proportions were determined by chi-square analysis, with a 95% confidence interval.

RESULTS

Characteristics of the Respondents

Of the 169 neonatologists practising in Canada, 121 (74%) agreed to participate in the study. All questions were answered except in the case of one respondent, who did not wish to answer the sociodemographic questions. All 31 Canadian Level III neonatal units were included in the survey, with a representative distribution throughout all nine Canadian provinces that have tertiary care neonatal intensive care units (i.e., all Canadian provinces except for Prince Edward Island). The respondents' characteristics are presented in Table 2. Canadian neonatologists of European descent made up the largest ethnocultural group, representing 70% of respondents overall (Table 2). Forty-five percent of clinicians had received their medical training and 74% completed their neonatal fellowships in a Canadian centre. Eighty percent of respondents had at least one child.

Attitudes Towards Resuscitation at Threshold of Viability

Respondents were asked to describe what they would do in response to a parental request to withhold resuscitation of their baby at 23 to 26 weeks' gestation. For newborns at 23 or 24 weeks' gestation, most respondents (98% or 80% respectively) agreed to withhold resuscitation with no or minimal constraint (Figure 1). At 25 weeks' gestation, 76% of the respondents would strongly recommend resuscitating a potentially "viable" fetus (moderate or strong constraint). About 42% would initiate resuscitation even if this was against parental request or they would obtain a court order to do so (strong constraint), although 24% would comply with a parental request to withhold intervention (no or minimal constraint). At 26 weeks' gestation, more than 97% would strongly recommend resuscitation (moderate or strong constraint) and 82% would resuscitate regardless of parental preference (strong constraint).

Kappa scores ranged between 0.577 and 0.752, 0.803 and 0.902, 0.767 and 0.901, and 0.665 and 0.837 for the scenarios at 23, 24, 25, and 26 weeks, respectively. This identifies a strong agreement in data categorization. When Kappa statistics were compared between pairs of investigators, agreement of scores was highest between the two neonatologist investigators (PML & SA), although it remained substantial with the third investigator (YK), who is not a neonatologist and who therefore provided internal validation of the data categorization process.

Although decisions to initiate resuscitation were based primarily on estimates of gestational age, many respondents, in their answers to open-ended questions, mentioned other attributes of "viability" at the time of initial delivery room assessment (vigorous baby, presence of heart rate, respiratory effort, weight and gestational age as estimated by clinical examination) that would influence their decisions.

Table 2. Sociodemographic characteristics of Canadian neonatologists surveyed (N = 121)

Age (median ± standard deviation)	50 ± 9.1 (range 31 to 75 years old)
Gender (female-to-male ratio)	6:4
Ethnocultural background (%)	
European descent	70
Asian	10
South Asian	8
Other	12
Number of years in practice as a neonatologist	16 ± 9.4 (range 1 to 47 years)
Country of medical school education (%)	
Canada	45
Other	55
Country of neonatal fellowship training (%)	
Canada	74
Other	26
Involved in neonatal follow-up (%)	19
Children at home (%)	80

Additional reasons mentioned were the presence of co-morbid conditions such as chorioamnionitis or congenital anomalies. A small number of respondents mentioned other factors such as the infant's gender and the use of antenatal steroids as potential variables to consider in their decision. When asked to clarify the factors that influence their decision, 12% of respondents (14/121) spontaneously stated that their responses were based on the Canadian Paediatric Society (CPS) Guidelines. Of those, most (11/14) cited 25 weeks as the gestational age in the scenarios at which they would mandate full resuscitation "according to the CPS guidelines." A few respondents cited either 24 weeks (2/14) or 26 weeks (1/14) as the gestational age at which they felt obliged to initiate resuscitation and neonatal intensive care. The level of constraint among these 14 respondents was not different from the entire cohort of 121 respondents ($P > 0.05$).

Regional Differences

Differences were observed in the attitudes of neonatologists to resuscitation at the threshold of viability, depending on the province of practice (Figure 2). The proportion of Canadian neonatologists who would strongly advocate resuscitation (level of constraint 2 or 3) differs by region more at 24 and 25 weeks' gestation than at other gestational ages (Figure 2). Differences were most obvious overall at 25 weeks (Figure 1). However, at 24 weeks there were substantial regional differences in two provinces (D and E), as well as smaller but obvious differences among other provinces (from 8% to 28%). Although there were too few respondents in some provinces (see legend, Figure 2) to make statistical inferences, the relatively large regional differences may still represent major clinical discrepancies in neonatal clinical care.

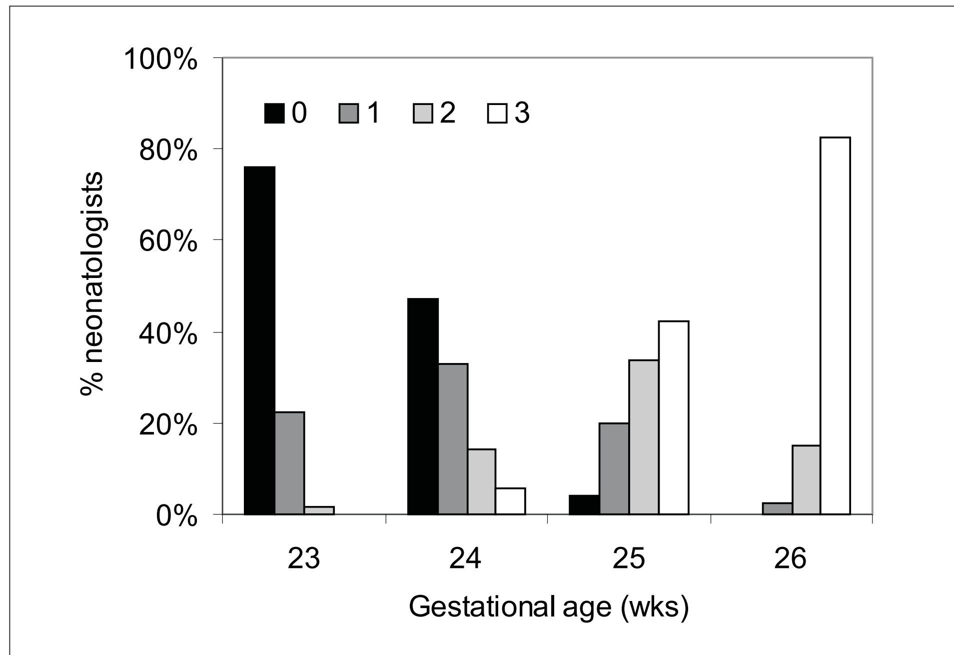
Sociodemographic and Other Cultural Variables

Constraint on parental decision-making authority was not significantly affected at any gestational age by variables such as age or gender of respondents, country of medical or neonatal fellowship education, and number of years of practice as a neonatologist, or experience with children at home. At 24 weeks, more neonatologists agreed (level of constraint 0 or 1) with a decision of non-resuscitation if they had a personal experience with a disabled close friend or relative (90% vs. 71%; $P = 0.01$).

DISCUSSION

We sought to explore the attitudes of Canadian neonatologists regarding initiation of resuscitation in the high-risk and extremely premature neonatal population. We obtained a representative sample of a majority of the neonatologists involved in tertiary care neonatology in Canada. We asked neonatologists whether they would consider a parental request not to resuscitate newborns at 23 to 26 weeks' gestation, using simple hypothetical scenarios through telephone interviews. We feel that this survey allows us to make valuable observations about the attitudes of Canadian neonatologists to interventions for neonates at the threshold of viability. Most respondents said that the

Figure 1. Constraint to resuscitation decisions at the limits of viability. Degree of constraint applied to a parental request not to initiate intensive care at birth at each gestational age (23 to 26 weeks' gestation). Data were categorized as *no constraint* (0) if they would agree not to initiate intensive care without reserve, *minimal constraint* (1) if they would agree after ascertaining that the parents were fully informed and competent to make the decision, *moderate constraint* (2) if they would strongly disagree and try to convince parents to allow resuscitation, and *strong constraint* (3) if they would resuscitate against parental wishes or obtain a court order to resuscitate.

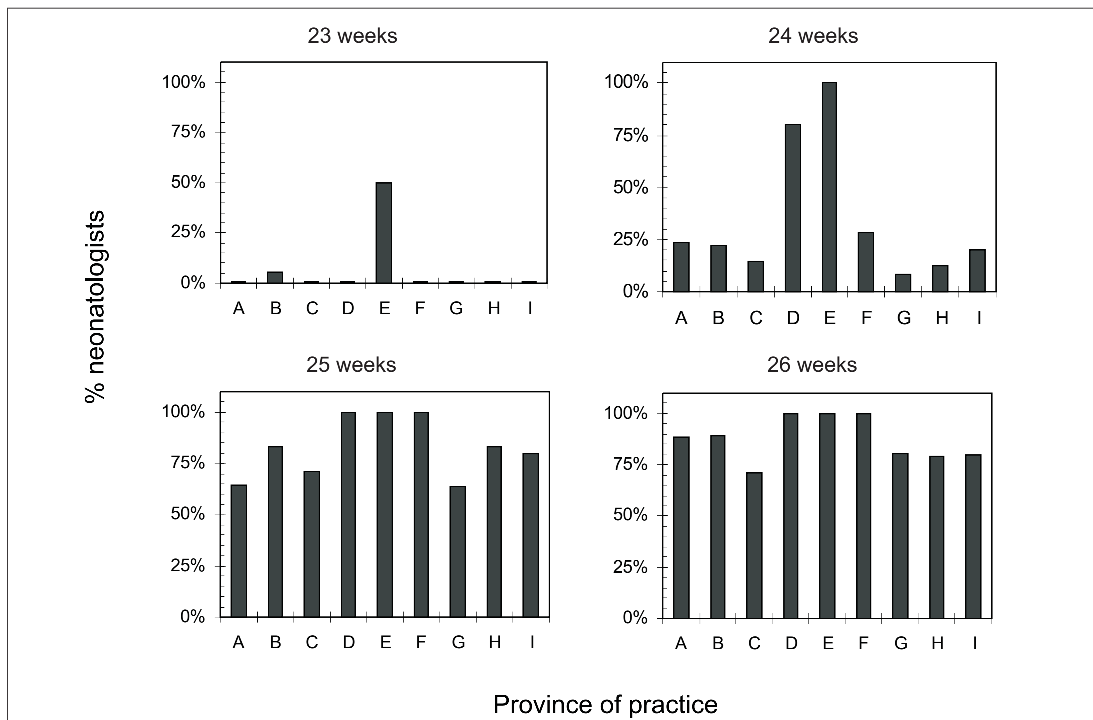


scenarios were realistic and that they had enough time to expand on their views.

The 1994 joint SOGC–CPS guidelines identify newborns at 23 to 24 weeks' gestation as falling within an area where "careful consideration should be given to the limited benefits for the infant."[4] In our survey, most neonatologists would accordingly agree with a parental decision to withhold resuscitation in the delivery room for newborns of these gestational ages. Complex sociodemographic influences, such as region of practice, personal experience with a disabled close friend or relative, or ethnocultural background, were more apparent in managing care of neonates at 24 or 25 weeks' gestation, reflecting a lack of consensus within this "grey zone" where a substantial degree of uncertainty exists with regard to outcomes and the long-term overall benefits of interventions. These observations are also consistent with the absence of medical consensus in the United States and European countries, where between 41% and 94% of neonatologists stated they would initiate intensive care of a viable 24 weeks' gestation newborn.[9,10] Nearly all neonatologists felt that resuscitation at delivery is in the long-term interests of a baby at 26 weeks' gestation.

For newborns at 25 weeks' gestation, 42% of Canadian neonatologists felt that the benefits of delivery room resuscitation largely outweigh parental wishes not to initiate treatment, although one quarter would agree to withhold intervention. The CPS guidelines recommend that all newborns at 25 weeks' gestation and above "receive neonatal intensive care treatment."[4] Reported neurodevelopmental outcomes for very preterm infants have not changed significantly in the past decade, despite an increased survival, although there have been improvements observed in some recent cohorts.[1,11–14] At 25 weeks' gestation, survival to discharge from the intensive care unit in Canada is estimated at around 75%.[6] However, 12% to 18% of these babies will suffer permanent disabilities, including severe cognitive impairment, non-ambulatory cerebral palsy, and severe to complete hearing or visual impairment.[15,16] What is considered a significant or acceptable risk for these children? Although the attitudes of a majority of Canadian neonatologists support the national guidelines and advocate for resuscitation of newborns at 25 weeks' gestation, several consider that it does require cautious consideration with parents. Given the differences observed in attitudes to resuscitation at 24 and 25 weeks' gestation between neonatologists in different Canadian provinces, we would

Figure 2. Regional differences in neonatologists' attitudes. The percentage of neonatologists combines the two highest levels of constraint (2 and 3 as detailed in the text) and is shown for each gestational age (each panel), by province of practice (A through I). The number of respondents (and, in brackets, percentages of total of neonatologists practising in tertiary care centres) for each province were, respectively, A: n = 18 (86%); B: n = 17 (71%), C: n = 7 (78%), D: n = 5 (56%), E: n = 2 (67%), F: n = 7 (87.5%), G: n = 36 (65%), H: n = 24 (57%), I: n = 5 (71%).



advocate for a moderation of current guidelines to reflect a more universal consensus rather than a stronger national policy.

Interestingly, many physicians emphasized the importance of counselling families about the importance of gender, use of antenatal corticosteroids, co-morbid factors such as chorioamnionitis or congenital malformations, and the importance of accurate determination of gestational age. This reflects the increasingly recognized influence of these variables on neonatal and long-term outcomes in this population.[15,17,18]

One potential limitation of this study is that it examines neonatologists' *attitudes* rather than *practices*. A comment made by several respondents was that our survey probably underestimated the degree of constraint applied in live situations, as it is easier to treat than not to treat. In that context, we believe that asking physicians whether they would agree *not to* resuscitate is more likely to discern diversity in attitudes, although we recognize that the situation in which parents expressly request a non-intervention is generally the exception rather than the rule (as noted by many study participants). Delivery of a high-risk premature newborn is undoubtedly fraught with a high degree of uncertainty regarding long-term prognosis. Ultimate decisions are often based on poorly validated early indicators of viability (e.g., ability to breathe, vigour at birth, need for immediate resuscitation).[19] In such uncertain situations, physicians tend to initiate resuscitation to buy time until more prognostic information is gathered (e.g., early neonatal course, brain imaging), although actual immediate survival and physicians' intentions do not differ substantially.[20] From our own experience with this survey, we can speculate that neonatologists might be more uncomfortable if they did not resuscitate viable babies that appeared to have a good prognosis at delivery than if they resuscitated less viable babies of lesser gestational age when the parents requested full intensive care.

It appears from our study that the attitudes of Canadian neonatologists in delivery room resuscitation decisions across Canadian perinatal centres for newborns at the threshold of viability were more influenced by demographic or sociocultural influences at 24 and 25 weeks' gestation than at other gestational ages. This decisional grey zone

likely reflects the complex variables involved in decision making, particularly when there is a higher degree of uncertainty regarding long-term neurological outcomes.[21]

Canadian physicians and the families they care for continue to face an enormous challenge with regard to decision making for initiation of care of an infant born at the threshold of viability. Our results generally support the current SOGC–CPS recommendations, although they highlight important nuances, mostly at 24 and 25 weeks. This study provides a basis for the re-evaluation of Canadian national guidelines, and we hope it will help obstetricians and neonatologists when counselling parents of newborns at the limits of viability.

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Appendix. Scenarios at the threshold of viability

In these 4 common neonatal scenarios, based on your local outcome statistics, how would you counsel the parents?

1. A woman is pregnant at 23 weeks. She is informed of the outcome at 23 weeks and does not wish resuscitation to be instituted. What would you do?
2. A woman is pregnant at 24 weeks. She is informed of the outcome at 24 weeks and does not wish resuscitation to be instituted. What would you do?
3. A woman is pregnant at 25 weeks. She is informed of the outcome at 25 weeks and does not wish resuscitation to be instituted. She is quite adamant. What would you do?
4. A woman is pregnant at 26 weeks. She is informed of the outcome at 26 weeks and does not wish resuscitation to be instituted. What would you do?