

Management of the newborn delivered at the threshold of viability

The threshold of viability—22 to 25 weeks' gestational age—is a difficult place for caregivers and parents alike. BC Children's and BC Women's has developed management guidelines to help parents and physicians make sound, ethical decisions.

ABSTRACT:

Background: Survival rates of extremely premature infants have been rising over the last 20 years. Because there is great variation in survival for newborns delivered at 22 to 25 weeks' gestational age (GA), management guidelines are needed. In an effort to produce such guidelines, BC Children's and BC Women's Hospital & Health Centre undertook a study to (1) calculate survival rates of infants born at BC Women's Hospital at 22 to 25 weeks' GA, (2) review long-term outcome data of neonates born at 22 to 25 weeks, (3) review existing recommendations, and (4) develop recommendations for managing the newborn delivered at the threshold of viability.

Methods: Survival rates of newborns delivered at 22 to 25 weeks' GA at BC Women's from 1999 to 2006 were calculated. Long-term outcome data, attitudes toward resuscitation, and management guidelines were reviewed. In order to prepare information sheets, recommendations regarding delivery room management were considered and parents of preterm infants were consulted.

Results: Survival rates indicate that the chance of survival increases dramatically from 22 to 25 weeks' GA. Long-term outcome data indicate that impairment rates are similar at 23, 24, and 25 weeks, with an overall 40% chance of normal neurodevelopmental outcome, a 30% risk of mild impairment, a 20% risk of moderate impairment, and a 10% risk of severe impairment at school entry. Based on survival and outcome data, current world literature, and ethical considerations, we proposed the following: At 22 weeks' GA (9% survival, 100% impaired), palliative care is recommended. At 23 weeks' GA (20% survival), intensive care is not recommended. At 24 weeks' GA (59% survival), treatment decisions are left with the parents. At 25 weeks' GA (80% survival), intensive care is recommended. With these recommendations in mind, we developed two parent information sheets and one physician information sheet.

Conclusions: Accurate information, parental input, and an understanding of ethical considerations are essential for decision making when a newborn is delivered at the threshold of viability.

Background

Initiating resuscitation and intensive care for preterm infants is generally accepted from 26 weeks' gestational age (GA) on.¹⁻³ By contrast, initial resuscitation and management of the extremely preterm infant born at 22 to 25 weeks' GA is controversial. Decision making in these cases requires consultation with the mother, her partner or support person(s), and the obstetrical and pediatric teams. The anticipated outcomes, management options, and the parents' opinions must be discussed, and consistent information

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about survival should be provided by all members of the health care team.

Even though survival rates of extremely premature infants have been rising steadily over the last 20 years,^{4,6} the variation in survival rates at 23 to 25 weeks' GA is still great enough to involve life-and-death obstetrical and neonatal decisions. In developed countries, reported survival rates of live-born infants are 0% to 46% at 23 weeks, 26% to 82% at 24 weeks, and 44% to 82% at 25 weeks.⁷ In 2006, survival rates that were adjusted for GA, severity of illness, and other confounding factors varied more than tenfold between the 24 Canadian neonatal intensive care units (NICUs) in the Canadian Neonatal Network.⁸

In BC, accurate GA assessment by first trimester ultrasound dating is a reliable and routine practice, performed in 88% of deliveries.^{5,9} Since GA is determined more accurately than fetal weight prior to delivery, GA-based survival rates are more useful for antenatal decision making and are the focus in this study.

Often overlooked is the denominator used for calculating survival rates. Survival rates increase as the denominator changes from total births (stillbirths and live births) to only live births to NICU admissions.⁵

The BC Women's Hospital & Health Centre is the largest of three tertiary-level perinatal and neonatal units in British Columbia. Attempts are made to transfer all women threatening to deliver extremely preterm infants to a tertiary-level unit since outcome is better for inborn than out-born infants.¹⁰ Ethical decision making at the threshold of viability requires a well-informed antenatal consultation process. At BC Women's the need for accurate information and consistency in antenatal counseling at 22 to 25 weeks' GA was the incentive for this study. Our objectives were to:

- Calculate survival rates at 22 to 25 weeks' GA for births at BC Women's using the following denominators: total births, live births, and births with active neonatal resuscitation.
- Review long-term outcome data of neonates born at 22 to 25 weeks' GA in British Columbia.
- Review existing recommendations and guidelines.
- Develop recommendations for managing the newborn delivered at the threshold of viability.

Methods

Collecting survival data

The hospital Decision Support Services obtained data from the British Columbia Perinatal Database Registry for all infants delivered at BC Women's at 22 weeks plus 0 days to 25 weeks plus 6 days between 1 April 1999 and 31 March 2006. Standardized data are collected on approximately 99% of all deliveries in British Columbia using the British Columbia perinatal forms. These and further data entered on designated data entry sheets by BC Women's clinical staff were then entered by trained abstractors into the British Columbia Perinatal Database Registry as part of the British Columbia Perinatal Health Program (formerly the Reproductive Care Program). The quality of the data was ensured by validation edits within the data entry software program and by quality checks. The best obstetric estimate was defined as GA (in completed weeks) based on early prenatal ultrasound and obstetrical care, unless the postnatal pediatric estimate of gestational age differed from the obstetric estimate by more than 2 weeks, in which case the pediatric estimate took precedence. Live birth was defined as the presence of a heartbeat or respirations. Active resuscitation in the delivery room was recorded by the physician attending the delivery and

included intubation, cardiac compressions, and resuscitation drugs, usually epinephrine, but did not include elective intubation. Routine delivery room care included drying, stimulating, and keeping an infant warm, with the provision of oxygen as needed. Results were tabulated by counts of all deliveries by GA: number of still births, live births, delivery room deaths, NICU deaths, subjects requiring emergency intubation, subjects who received cardiac compressions or resuscitation drugs, and mode of delivery. Survival rates were calculated for all births, all live births, and all subjects requiring active resuscitation. Operative delivery rates were calculated for stillbirths and live births, and 95% confidence intervals were calculated for survival rates by each week of GA. A statistically significant difference between survival rates at each week GA was sought using a chi-squared test for trend. A probability value of less than .05 was deemed to be significant.

Collecting long-term outcome data

PubMed was used to review international data published about survival and long-term neurodevelopmental outcomes of extremely premature and extremely low birth weight infants. For local data, we relied on the Neonatal Follow-Up Programme (NFUP) at BC Children's and BC Women's Hospitals (C&W), which collects long-term outcome data on babies born in British Columbia at less than 26 weeks' GA. These data are derived from multidisciplinary standardized assessments at 4, 8, and 18 months corrected age and 3 and 4 1/2 years of age. The NFUP used definitions of normal, mild, moderate, and severe impairments adapted from the EPICure study¹¹ to evaluate the outcome at 4 1/2 years of 341 survivors born at 22 to 25 weeks' GA between 1983 and 2000.¹² Mild

Table 1. Survival rates for all births and live births,* BC Women's Hospital, 1999 to 2006.

GA (weeks)	All births	Live births	Still births	Delivery room deaths	NICU deaths	NICU survivors	All birth survival rate (95% CI) [†]	Live birth survival rate (95% CI) [†]
22	57	36	21	28	6	2	3.5% (.4, 12.1)	5.5% (.7, 18.7)
23	59	40	19	17	14	9	15.3% (7.2, 27.0)	22.5% (10.8, 38.4)
24	96	75	21	12	20	43	44.8% (34.6, 55.3)	57.3% (45.4, 68.7)
25	98	90	8	2	15	73	74.5% (64.7, 82.8)	81.1% (71.5, 88.6)
Total	310	241	69	59	55	127	41%	53%

*Numbers in all columns represent frequency unless noted otherwise.
[†]Statistically significant difference in survival between weeks GA, $P < .0001$

Table 2. Resuscitation and outcome.*

GA (weeks)	No resuscitation	Survival rate	Intubation only	Survival rate	Intubation and compression	Survival rate	Any resuscitation	Survival rate [†]
22	28	1/28 (4%)	6	1/6 (17%)	2	0	8	1/8 (13%)
23	21	4/21 (19%)	17	5/17 (29%)	2	0	19	5/19 (26%)
24	17	11/17 (65%)	46	27/46 (59%)	10	4/10 (40%)	56	31/56 (55%)
25	41	33/41 (81%)	42	35/42 (83%)	5	4/5 (80%)	47	39/47 (83%)
Total	107	49/107 (46%)	111	68/111 (61%)	19	8/19 (42%)	130	76/130 (59%)

*Numbers in all columns represent frequency unless noted otherwise.
[†]Statistically significant difference in survival between weeks GA, $P < .001$

impairment was defined as one or more of the following: fine motor test score more than two SD below the mean, one facet of an intelligence quotient (IQ) two SD below the mean, unilateral or mild hearing impairment (25 to 40 decibels), or the need for glasses or strabismus. Moderate impairment was defined as one or more of the following: cerebral palsy, IQ between two and three SD below the mean, sensorineural hearing loss corrected with aids, and visual impairment worse than 20/70 in the better eye with optimal correction. Severe impairment was defined as one or more of the following: the inability to walk 10 steps independently, IQ more than three SD below the mean, profound sensorineural hearing loss not corrected with hearing aids, and legal blindness.

Reviewing existing recommendations

PubMed was used to review the literature regarding recommendations or guidelines for the care of babies born at the threshold of viability. Personal communications were also used to obtain information about existing recommendations.

Developing recommendations and information sheets

The development of recommendations began with an educational round for trainees and staff of the Division of Neonatology at BC Women's. Results of a literature review and a summary of ethical considerations were then presented to the Division of Neonatology as the first step in consensus-building. A draft proposal was developed from this discussion and reviewed

locally with neonatal nurses, neonatal physicians and trainees, family physicians, obstetricians, obstetric nurses, and obstetric trainees. Over the course of 2 years (April 2005 to May 2007), the proposal resulting from this preliminary consultation was reviewed with neonatologists, pediatricians, and obstetricians throughout BC in pediatric and multidisciplinary obstetric grand rounds and through telehealth links.

During this process, the need for parents to have concise and comprehensible written information emerged. A convenience sample of parents with extremely premature babies who were in the NICU but were not acutely ill provided input into the development of some parent information sheets designed to serve as an adjunct in the antenatal consultation process and to

present consistent information about survival and neurodevelopment outcomes. Two focus groups made up of NICU parents as well as the parents of babies who were enrolled in the NFUP provided additional input. A physician information sheet that expanded on the content of the parent information sheets was also developed. Final recommendations and the draft information sheets were presented to a multi-disciplinary group at the BC Neonatal Conference in October 2007.

Results

Survival rates

There were 310 deliveries at 22 to 25 weeks' GA at BC Women's during the 6-year study period. The overall survival rate was 41% for all deliveries and 53% for live births, with clinically and statistically significant ($P < .0001$) increasing survival rates for each week GA for all births and live births (Table 1). There were only two survivors at 22 weeks' GA and 9 survivors at 23 weeks' GA. Stillbirths and delivery room deaths occurred most frequently at 22 weeks' GA. The dramatically increased chance of survival from 22 to 25 weeks' GA is shown in Figure 1. The 95% confidence intervals that are included illustrate the degree of uncertainty with the available sample size.

Survival rates by type of delivery room resuscitation are shown in Table 2. At the younger gestational ages, both no resuscitation and the provision of intubation and cardiac compressions were associated with lower survival rates. There were no survivors among the four neonates who received cardiac compressions at 22 and 23 weeks' GA.

Cesarean section rates were found to vary dramatically by GA and between live births and stillbirths (Table 3).

Table 3. Cesarean section (CS) rates.

GA (weeks)	Stillbirth CS rate	Livebirth CS rate	Overall CS rate
22	4.8%	2.8%	3.5%
23	5.3%	17.5%	13.6%
24	0.0%	48.0%	37.5%
25	0.0%	63.3%	58.2%
26	18.2%	64.4%	59.2%
Total	5%	47.9%	39.5%

Long-term outcome data

The National Institute of Child Health and Human Development (NICHD) identified significant differences in impairment rates (25% to 69%) in extremely low birth weight survivors (401 to 1000 g) at participating NICUs.¹³ The following factors were associated with a worse neurodevelopmental outcome: male gender, multiples, and need for active resuscitation. The following factors were associated with better outcomes: prenatal care, antenatal steroids, and higher birth weight.¹³

In British Columbia, long-term neurodevelopmental impairment rates of extremely low birth weight survivors have not changed over the last 20 years.¹⁴ Our local data, derived from survivors born between 1983 and 2000 and assessed at 4 1/2 years or the most recent visit, showed that of the two survivors at 22 weeks' GA one had a moderate impairment and one had a severe impairment. There were no significant differences in survivors at 23, 24, and 25 weeks' GA, with an overall 40% chance of normal neurodevelopmental outcome, 30% risk

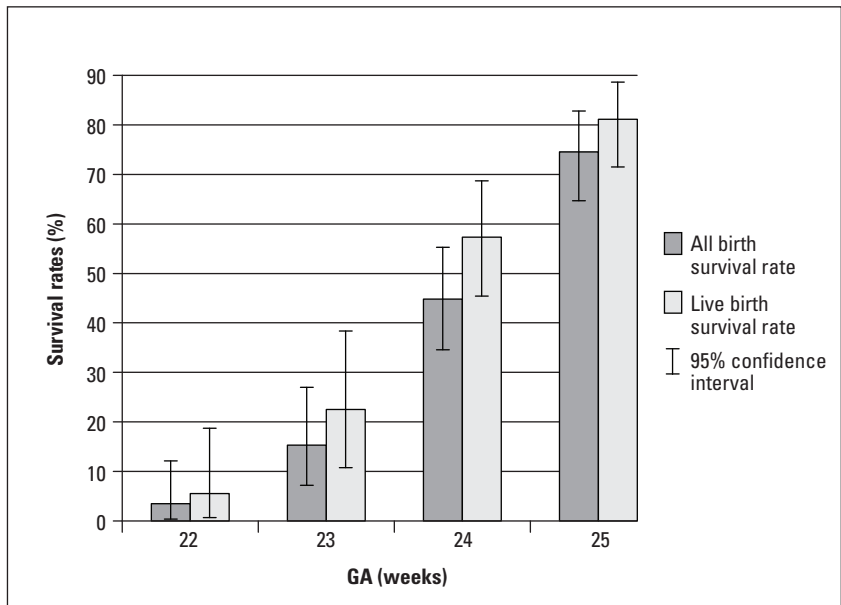


Figure 1. Survival rates with 95% confidence intervals



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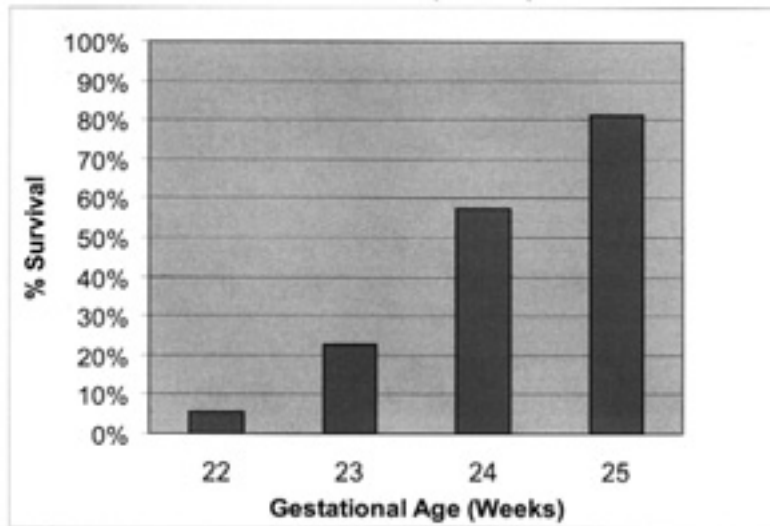
Parent Information Sheet #1



A new baby is an exciting and wonderful event. If the baby is very premature this can be stressful. Sometimes you and your doctor need to plan how to best care for your baby even before the baby is born. We want you to have the most up-to-date information about how these very premature babies do. This will help you with decisions at this time.

Each baby is different. The graph below shows survival for babies born at Children's and Women's Hospitals in British Columbia. This information is similar to survival rates for other premature babies born in Canada and the U.S.A.

What Are The Chances My Baby Will Go Home?



*Gestational Age = number of weeks when baby is born (for example, 22 weeks= 22 weeks plus 0 days to 22 weeks plus 6 days).

Every day is important; survival improves by about 2-4% per day.

Other factors, not just being very premature, can make survival rates even lower. These include:

- Multiple births (twins, triplets, or more)
- Babies with genetic problems
- Infection in the uterus
- Leaking of fluid from the uterus for days or weeks before delivery
- Poor growth of the baby before birth
- Being a boy

The needs of each family and baby may be different and will be fully discussed with you.

Based on our outcomes and recommendations from other nurseries like ours in the world, our advice is:

- Before 23 weeks: Intensive care* will not be offered. Palliative care* will be provided.
- 23 weeks: Intensive care is not advised
- 24 weeks: Intensive care or palliative care
- 25 weeks: Full intensive care recommended

***Intensive care** = all possible life-saving treatments, including breathing machines and blood tests

***Palliative care** = all possible comfort care, no aggressive life-saving treatments

We know you will be discussing this, as well as information about other outcomes for your baby (Parent Information Sheet #2), with your doctor. We hope this information is helpful for you and your family.



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Figure 2. Parent information sheet 1.

of mild impairment, 20% risk of moderate impairment, and a 10% risk of severe impairment.¹²

Learning impairments are common in the extremely preterm infant and can only be ascertained at school age. In a population of 115 school-age survivors weighing less than 800 g at birth, Whitfield and colleagues¹⁵ showed that 14% had severe or multiple neurosensory disabilities, 13% had a borderline IQ of 70 to 84, and 47% of the unimpaired had a learning disorder.

Existing recommendations

Various groups¹⁶⁻²⁰ have studied the attitudes of neonatologists and other health care providers to resuscitation and the initiation of intensive care treatment at the threshold of viability (Table 4). The majority would either strongly advocate resuscitation or resuscitate all babies at 25 weeks' GA, even against parental wishes, whereas very few would advocate resuscitation at 22 and 23 weeks' GA. Consequently, at 24 weeks' GA (where there is the least consensus) parental choice plays the most significant role in the decision. In a recent American study,¹⁸ of this "gray zone" at 23 and 24 weeks' GA, only one-third of the neonatologists polled reported that parental preference would determine whether they attempted resuscitation. Although the majority reported that they wanted to "see what the infant looked like" before making this decision, the appearance of the baby at the time of delivery was not predictive of survival or impairment. In Australia, the factors ranked highest in affecting clinicians' decisions were "parental wishes" together with "condition at birth."¹⁹

Recommendations for resuscitation at the threshold of viability are summarized in Table 5. The most recent Canadian statement was released

Table 4. Published studies on attitudes of health care providers to resuscitation at various gestational ages.

Percentage of health care providers who recommend resuscitation				
GA (weeks)	Lavoie ¹⁶	Lavin ¹⁷	Singh ¹⁸	Peerzada ²⁰
22	n/a	2%	n/a	0%
23	3%	12%	4%	15%
24	20%	49%	59%	58%
25	76%	85%	93%	93%

Table 5. Published guidelines for resuscitation at various gestational ages.

Recommendations			
GA (weeks)	Australia, 2006: Lui ¹⁹	Canada, 1994: CPS ²¹	England, 2006: Nuffield ³
22	Palliative care	Palliative care, parents can request resuscitation	No resuscitation
23	Discourage resuscitation	Parental decision	Parental decision
24	Option to withhold	Parental decision	Resuscitation
25	Resuscitation with option to withhold	Resuscitation	Resuscitation

Table 6. BC recommendations for management at the threshold of viability.

GA (weeks)*	Recommendation
<23	Do not resuscitate and provide palliative care
23	Discourage resuscitation and intensive care
24	Provide intensive care or palliative care
25	Provide intensive care with option of palliative care

*Completed weeks = number of weeks of gestation (e.g., 22 weeks = 22 + 0 days to 22 + 6 days)

in 1994 by the Canadian Paediatric Society.²¹ In 2001, the British Columbia Reproductive Care Program²² published a general "obstetric guideline" that did not consider the role of the parents in the decision-making process but did include a stipulation that individual circumstances must always be taken into account.

The 2002 American Academy of Pediatrics (AAP)² statement indicated that such decisions are to be based on fetal/infant condition and prognosis,

and made jointly by informed parents and physicians. In addition, parental choice is to be respected within the limits of medical feasibility and appropriateness.

In the United Kingdom, the Nuffield Council on Bioethics³ states that at 24 weeks' GA, intensive care should be initiated unless both the doctor and parents agree that it is not in the best interests of the child in light of the baby's specific condition. At 23 weeks' GA, it is the parents who



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Parent Information Sheet #2

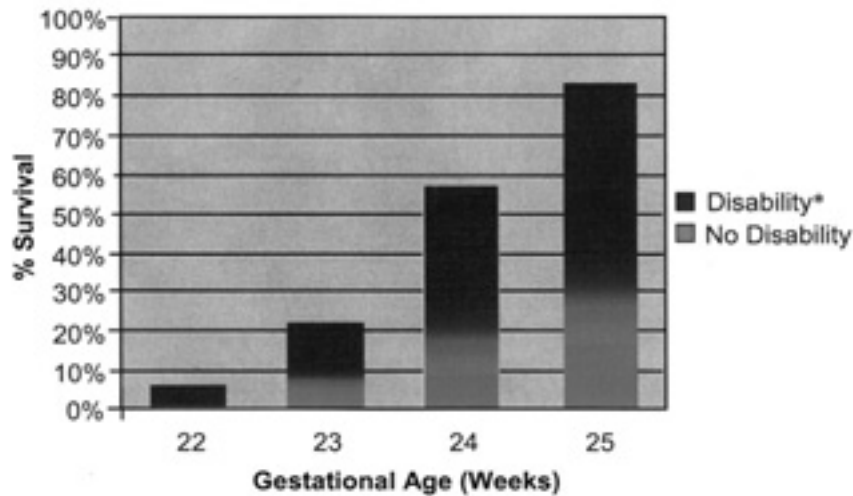


Like other children, babies born early have their own strengths and weaknesses. The following information is provided to help you better understand the concerns if your baby is born very early. We have defined different kinds of disabilities (problems) as follows:

Disability	Movement	Intelligence	Hearing / Speech	Eyesight
Mild	Clumsy or difficulties with paper and pencil work	Learning difficulties in schoolwork	Mild hearing loss	Needs glasses
Moderate	Cerebral palsy but can walk by themselves	Slower than average, but learns with support	Permanent hearing problem corrected with hearing aids	Poor eyesight, even with glasses
Severe	Unable to walk without help	Very low, will need care lifelong	Deaf: cannot hear even with hearing aids	Blind

More than half of children born very prematurely have learning disabilities.

What Are the Chances My Baby Will Have a Disability?



*At 23-25 weeks there is a 30% chance of mild disability, 20% chance of moderate disability, and 10% chance of severe disability.

- After the baby is born there may be more information about the chances that the baby will likely have long term problems.
- A baby's family and surroundings are also important for your baby's development.
- If you have any questions, please ask your doctor.



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Figure 3. Parent information sheet 2.

decide, although there is no legal obligation for futile treatment if the doctor's clinical judgment is that the baby will not survive. At 22 weeks' GA, resuscitation should only occur within the realm of clinical research and hence with the parents' informed consent.

Recommendations for BC

Taking into account local neonatal survival and outcome data, current world literature, and ethical considerations, we developed medical recommendations for British Columbia, as summarized below and in **Table 6**.

At 22 weeks' GA, there are very few survivors and no intact survivors and it would be unconscionable to provide intensive care. At 23 weeks' GA, where there is a chance of intact survival (though it is much more likely that the baby will die or survive with a disability), the recommendation is to provide intensive care treatment only at the request of well-informed parents. At 24 weeks' GA, where there is more than a 50% chance of death or severe disability and a smaller chance of intact survival, the recommendation is that treatment decisions should remain with the parents. At 25 weeks' GA, where survival improves markedly and there is less than a 50% risk of death or severe disability, the recommendation is to provide full resuscitation and intensive care. However, as there is still a significant chance of death or severe disability and less than a 50% chance of intact survival, if well-informed, competent parents elect not to accept intensive care treatment for their infant this care should not be imposed. Additionally, some babies born at 25 weeks' GA do not require resuscitation, and there must be some room for discussion about the baby after birth. In cases where the gestational age is uncertain, it is necessary to evaluate all obstetrical infor-

mation to assess the range of possible gestational ages, estimated fetal weight, and potential confounding factors. Parents' wishes throughout the spectrum of possible gestational ages must be elicited. In the face of uncertainty about GA, resuscitation can be provided and whether to continue intensive care or not can be reviewed with parents afterward.

Parent and physician information sheets

The development of the parent information sheets (**Figures 2 and 3**) and the physician information sheet (**Figure 4**) was completed after the multidisciplinary group review in 2007. The final versions of the parent sheets were written at a grade 8 reading comprehension level and were approved by the Patient and Family Education Committee at C&W. Parents who provided feedback during the development process identified the need for two separate counseling sessions: one to review survival and a second to review neurodevelopmental outcomes. Such a need was also identified in a recent study by Payot and colleagues,²³ who confirmed that making decisions about infants born at the limits of viability requires taking into account the long-term outcomes and the quality of life of survivors. Survivors' abilities, disabilities, and quality of life exist on a continuum. Parents vary regarding where they would choose death/no resuscitation on this continuum. In the literature, developmental outcome is usually reported as a dichotomous "normal or abnormal," an approach that does not facilitate counseling using families' preferred definition of a "significant disability."

Conclusions



The dramatic difference in live-birth survival rates between 22 and 25 weeks' gestational age (from 6% to

81%) confirms that with our current management practices 22 to 25 weeks' GA is the threshold of viability. Our recommendations were developed by neonatology staff with input from key stakeholders in response to a clinical need for guidelines on managing the newborn delivered at the threshold of viability.

Although we did not rely on a priori criteria when developing recommendations, we did consider suggestions first published in 1995 from the NICHD Neonatal Research Network.²⁴ These state that provision of intensive care should be mandatory when the risk of death or severe morbidity is less than 50%, and that such care is optional at 51% to 75%, investigational at 76% to 95%, and unreasonable at greater than 95% risk of death or severe morbidity. Even with the best evidence on survival and long-term outcomes, recommendations for management at the threshold of viability are based on value judgments. There will therefore be some individuals, both physicians and parents, who will not agree with these recommendations. The intent of this article is to permit informed discussion of these recommendations by providing adequate methodological detail about the survival and long-term outcome data that formed the foundation for the recommendations.

We have also provided information to facilitate adaptation of the data to the individual case. For example, the survival rate denominator can be changed to all births if there is a significant risk of fetal demise or intrapartum death. Other factors, such as gender, multiple pregnancy, intrauterine growth, and treatment with antenatal steroids, also affect survival and need to be considered.

As it is difficult to calculate survival rate by intent to treat, cesarean section rate and survival rate for resuscitated



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Physician Information Sheet

This sheet provides counseling tips and supplementary information for use with the Parent Information Sheets. The Parent Information Sheets are only to be used in conjunction with face to face consultation.

Parent Information Sheet #1:

- Survival rates have improved. There is significant variation in survival between Neonatal Intensive Care Units. In British Columbia, survival rates are in the mid to high range of those reported in the USA and Europe.¹
- The survival rates shown are derived from a study of 310 deliveries at 22-25 weeks gestation at British Columbia's Women's Hospital from 1999-2006.¹ The rates shown are for all *live* births. If there is concern about fetal well being, use survival rates for all births (*including live and still births*) (22 wks- 4%, 23 wks-15%, 24 wks- 45%, 25 wks-75%).
- Delivery in other than a tertiary level centre is associated with a lower survival rate.

Parent Information Sheet #2:

- The data set used to calculate the impairment rates consisted of 350 children born between 1983-2000 followed in the British Columbia Neonatal Follow-Up Programme.¹ Most of the results are based on assessments at 4 ½ years of age.
- There was no difference in impairment rates between children born at 23, 24 and 25 weeks gestation. The 2 survivors at 22 weeks gestation both had moderate to severe impairments.
- The graph is a compilation of different data sets. It assumes that the impairment rates from 1983-2000 will apply to the 1999-2006 population cohort that was used to calculate survival.
- Impairment rates vary between centres and overall have not changed over the last 20 years.
- Better outcomes are associated with: prenatal care, being female, singletons, higher birth weight.²
- As learning disabilities cannot be diagnosed at 4 ½ years, risk factors for learning disabilities were included in the mild problem category.
- Shading in the graphs was used to portray that all individuals vary in their abilities and children with "problems" vary in the severity and number of those problems.

Counseling tips:

- Term infants may have long term developmental concerns (10-15% will have mild disabilities).
- Extremely preterm babies have more health and developmental problems than term babies.
- These problems range from mild to severe but most are mild (30% mild, 20% moderate, 10% severe) using the definitions above.
- Developmental abnormalities take time before they can be identified. Severe problems are usually apparent by 18 months corrected age, but learning disabilities, clumsiness, attention and behavior problems may not be evident until school age.
- More than one half of children born extremely preterm have a learning disability.

References:

1. Synnes AR, Buchanan L, Ruth C, Albersheim S. Management of the newborn delivered at the threshold of viability. Submitted to BCMJ.
2. Vohr BR, Wright LL, Dusick AM, Mele L, Verter J et al. Neurodevelopmental and functional outcomes of extremely low birth weight infants in the National Institute of Child Health and Human Development Neonatal Research Network, 1993-1994. *Pediatrics* 2000;105:1216-26.

Figure 4. Physician information sheet.

newborns are provided as less-than-perfect proxies. At 22 to 23 weeks' GA, our data show a low cesarean section rate, high stillbirth rate, and a large proportion of delivery room deaths, suggestive of a less aggressive approach at these gestations. Not surprisingly, the survival rate is higher when neonatal resuscitation is provided. Conversely, at 25 weeks, over 60% of live births are delivered operatively and stillbirths and delivery room deaths are much less frequent. The survival rate of 25-week GA babies who do not receive active neonatal resuscitation is over 80%, reflecting their stable condition at birth rather than lack of intent to treat.

The operative delivery rates and resuscitation outcome data are helpful in interpreting our survival rates compared with other sites. Survival rates at BC Women's fall within the range reported for NICUs elsewhere. At 23 weeks' GA, 23% survival is in the midrange between 0% and 46%.⁷ With increasing GA, and specifically at 25 weeks' GA, our survival rate of 81% is on par with the highest in Europe and the United States.^{7,25,26}

A limitation of this study is that the population selected included only neonates born at BC Women's and did not include deliveries at the other two NICUs in BC, nor did it include out-born babies transported to BC Women's after delivery, who have a lower survival rate.

Decision making at the limits of viability must address not only whether survival is possible but also whether survival is in the child's best interests given what is known about the morbidities and quality of life of survivors. A challenge in interpreting outcome studies is that impairments and abilities only become apparent over time, and accuracy in prognostication for individual neonates is poor. Studies on older children provide more

accurate evaluation of eventual adult functioning, but the NICU care of these children may not reflect current practices. Thus, we have relied on data about cerebral palsy, developmental delay, and sensory impairments that

are not stand-alone documents and should not be used instead of an antenatal consultation, but rather as an adjunct to this process. They are intended to provide consistent information for those undertaking antena-

The survival rate of 25-week GA babies who do not receive active neonatal resuscitation is over 80%.

can be reasonably ascertained at 18 to 24 months corrected age, cognitive impairment as measured by intelligence quotients at 3 to 4 years, and learning disabilities at school age.

The neurodevelopmental outcomes measured reflect the spectrum of impairment from mild to severe. The outcome data are not only local and current but try to promote dialogue regarding what degree of impairment is significant for the individual family.

In relation to existing guidelines, our recommendations are more consistent with the recently published American,¹⁷ Australian,¹⁹ and British³ recommendations. They embrace the concepts expressed by the AAP but provide more concrete advice. Unlike the 1994 CPS guidelines,²¹ our guidelines do not recommend intensive care at parental request at 22 weeks' GA. At 25 weeks' GA, where the CPS simply recommends providing intensive care, we specify that intensive care may be withheld at the request of fully informed parents.

The parent information sheets developed during this study are designed to help with decision making. They

are not stand-alone documents and should not be used instead of an antenatal consultation, but rather as an adjunct to this process. They are intended to provide consistent information for those undertaking antena-

tal consultations. As with any new "intervention" in the NICU, these sheets will be re-evaluated as we collect data about their utility. We will also be assessing the utility of the physician information sheet through feedback from physicians. We recognize that any recommendations for management at the threshold of viability can never be more than a guideline in view of the complex ethical considerations (see accompanying article on page 509) medical uncertainty, and unanswered questions involved. We also recognize that our recommendations will need to be re-evaluated on an ongoing basis as new outcome data become available.

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Competing interests

None declared.

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