Predicting Long-Term Survival Without Major Disability for Infants Born Preterm

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Objective To describe the long-term neurodevelopmental and cognitive outcomes for children born preterm.

Study design In this retrospective cohort study, information on children born in Western Australia between 1983 and 2010 was obtained through linkage to population databases on births, deaths, and disabilities. For the purpose of this study, disability was defined as a diagnosis of intellectual disability, autism, or cerebral palsy. The Kaplan–Meier method was used to estimate the probability of disability-free survival up to age 25 years by gestational age. The effect of covariates and predicted survival was examined using parametric survival models.

Results Of the 720 901 recorded live births, 12 083 children were diagnosed with disability, and 5662 died without any disability diagnosis. The estimated probability of disability-free survival to 25 years was 4.1% for those born at gestational age 22 weeks, 19.7% for those born at 23 weeks, 42.4% for those born at 24 weeks, 53.0% for those born at 25 weeks, 78.3% for those born at 28 weeks, and 97.2% for those born full term (39-41 weeks). There was substantial disparity in the predicted probability of disability-free survival for children born at all gestational ages by birth profile, with 5-year estimates of 4.9% and 10.4% among Aboriginal and Caucasian populations, respectively, born at 24-27 weeks and considered at high risk (based on low Apgar score, male sex, low sociodemographic status, and remote region of residence) and 91.2% and 93.3%, respectively, for those at low risk (ie, high Apgar score, female sex, high sociodemographic status, residence in a major city).

Conclusions Apgar score, birth weight, sex, socioeconomic status, and maternal ethnicity, in addition to gestational age, have pronounced impacts on disability-free survival. *(J Pediatr 2019;215:90-7)*.

Complications of preterm birth, which affect 1 in 10 babies globally, continue to be the most common causes of neonatal death.[1] Furthermore, many survivors face short- and long-term complications, including neurodevelopmental, behavioral, sensory, and respiratory conditions and repeated hospitalizations.[2] The increasing use of active interventions, such as antenatal corticosteroids and surfactants, has brought significant improvements in both survival and neonatal morbidity of preterm infants over the past 20 years.[3]

Children born preterm are at increased risk of neonatal and postneonatal deaths compared with those born full term, with greater absolute and relative risks at lower gestational ages.[4] In Western Australia (WA), infants born at 24-31 weeks of gestational age are at a 125-fold increased risk of neonatal death and a 14-fold increased risk of postneonatal death compared with full-term infants.[4] Of particular interest has been the rates of and impact on survival of life-sustaining interventions for infants born at 22-24 weeks of gestation.[5] The proactive management of extremely preterm infants has been shown to be associated with lower mortality.[6-8] Although proactive management was not associated with any increase in morbidity (ie, chronic lung disease, intraventricular hemorrhage, and retinopathy of prematurity) in a Swedish cohort,[6] it was associated with an increased rate of cerebral palsy compared with population-based cohorts in the US and The Netherlands.[7] Moreover, the prevalence of cerebral palsy (estimated at 2.5/1000 live births[9]) increases with decreasing gestational age.[10] A review of the literature on preterm birth and childhood psychiatric conditions showed an increased prevalence of autism spectrum disorder (ASD), as well as a 2- to 3-fold relative risk for attention deficit hyperactivity disorder in very preterm populations.[11] Current population estimates of the prevalence of ASD vary from 5.1 to 21.9/1000, and the population prevalence of intellectual disability is estimated as 17/1000 live births.[12,13]

ASD	Autism spectrum disorder
HR	Hazard Ratio
IDEA	Intellectual Disability Exploring Answers
IRSD	Index of Relative Socio-Economic Disadvantage
MNS	Midwives Notification System
WA	Western Australia
WARDA	Western Australia Register of Developmental Anomalies

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Two meta-analyses investigating cognitive outcomes at age 4-17 years for children born preterm found that these children scored approximately 12 IQ points below their term-born peers.[14,15] This may be an underestimate, given that many preterm infants will not have survived to the age at assessment and some studies excluded more severely affected children. A population-based Swedish study demonstrated that almost 65% of those born at 22-26 weeks of gestation had no cognitive impairment when assessed at 2.5 years of age. However, 24% scored between 1 and 2 SD below the mean on a developmental test, and a further 11% scored >2 SD below the mean.[16] A later follow-up of these children at 6.5 years of age found that only 36% had no cognitive impairment, and one-half of the children found to have an intellectual disability at 6.5 years of age had not previously been identified at the 2.5-year assessment.[17] A US study demonstrated a clear difference in preschool outcomes between infants born very preterm at 23-24 weeks of gestation (mean IQ, 89.1) and those born at 25-26 weeks of gestation (mean IQ, 102.5).[18] A French study followed a population-based cohort of preterm infants (22-34 weeks) and found that the percentage discharged without severe neonatal morbidity was 34% for those born at 24-26 weeks, 81.3% for those born at 27-31 weeks, and 96.8% for those born at 32-34 weeks.[19]

Preterm birth has a complex etiology, and a range of overlapping risk factors have been identified in the empirical literature.[20] These include reproductive history, maternal medical conditions, genetics, complications of pregnancy and delivery, and a raft of more distal, social determinants.[21] There is consistent evidence of socioeconomic disparities in preterm birth rates—both within and across countries—although the causal pathways and the relative contributions of individual, family, and community factors are not well understood.[22,23] The most socioeconomically disadvantaged WA mothers were at 5-fold greater risk of having a child with a mild or moderate intellectual disability compared with the least disadvantaged mothers.[24] Race/ethnicity is also a prominent risk factor for preterm birth and subsequent life outcomes.[25] In those born at <26 weeks, 1-year mortality was lower for black infants compared with white and Hispanic infants, but for those born at >32 weeks, the reverse was true, with higher 1-year mortality for black infants.

Although numerous studies have investigated survival in preterm infants and some have investigated disability in survivors, few have combined both of these outcomes. The availability in WA of linked population-based databases on intellectual disability, autism, cerebral palsy, births, and deaths[26] allowed us to examine the likelihood of disability-free survival into adulthood and to investigate how this also may be influenced by sociodemographic and perinatal factors.

Methods

This was a retrospective cohort study of all live births in WA occurring between January 1, 1983, and December 31, 2010, identified in the Midwives Notification System (MNS). Although the scope of the MNS is 20 weeks of gestation and above or birth weight of at least 400 g, we restricted the cohort to ≥22 weeks as neonatal intensive care admission is generally not provided for infants <22 weeks. Gestational age was categorized as 22-23, 24-27, 28-31, 32-34, 35-36, 37-38, 39-41, and >42 weeks. Deaths up to December 31, 2010, were identified through linkage to the WA Registry of Births, Deaths, and Marriages. Children not recorded as deceased were censored on December 31, 2010, the end of the study period.

Outcomes

Children diagnosed with an intellectual disability or ASD by 2012 were identified by linkage to the IDEA (Intellectual Disability Exploring Answers) database, which ascertains cases born since 1983 through the WA Disability Services Commission and the WA Department of Education.[13] The clinical diagnosis of intellectual disability is generally supported using standardized measures of intelligence, which derive an IQ of ≥2 SD below the population mean, equivalent to a score of approximately ≤70.[27] ASD is a neurodevelopmental disorder characterized by deficits in 3 domains: social relatedness, communication, and repetitive restrictive patterns of behavior.[27] Approximately two-thirds of children with ASD had a comorbid intellectual disability.[13] Children born between 1983 and 2010 and diagnosed with cerebral palsy by 2012 were identified through the WA Register of Developmental Anomalies (WARDA), and 40% of these children had a comorbid intellectual disability. Children diagnosed with an intellectual disability caused by a postnatal event (n = 122), such as an accident or infection, were excluded from the disability group.

Covariates

Birth-related variables from the MNS used in our analyses included maternal age group (<20, 20-34, or >34 years), ethnicity (Caucasian, Aboriginal/Torres Strait Islanders, or other), marital status (married, never married, formerly married, or unknown), infant sex (male or female), birth year, birth weight (400-1499, 1500-2499, or >2500 g), parity (0, 1, 2, 3, 4, or 5+), 5-minute Apgar score (0-6 or 7-10), onset of labor and mode of delivery (spontaneous vaginal, induced vaginal, elective caesarean delivery, or emergency caesarean delivery), and smoking status during pregnancy (no, yes, or missing). We used an area-based measure of socioeconomic status, the Socio-Economic Indexes for Areas Index of Relative Socio-Economic Disadvantage (IRSD), categorized into 6 quantiles, with higher index scores reflecting areas with relatively high advantage (derived at the collection district level), which was linked to the MNS based on maternal address at birth.[26] We used the Accessibility/Remoteness Index of Australia classification as a measure of geographic remoteness (major cities, inner and outer regional areas, and remote and very remote areas).

Statistical Analyses

Maternal and child characteristics of the in-scope live births were summarized using mean with SD or proportion, as

appropriate. Gestational age at birth was the exposure variable, and death or diagnosis with intellectual disability, autism, or cerebral palsy was the outcome variable.

For survival analysis, all individuals were followed until death or a diagnosis of intellectual disability, autism, or cerebral palsy or were censored at December 31, 2010, whichever occurred first. The Kaplan–Meier method was used to estimate the survival functions, and the log-rank test was used to compare survival among categories of explanatory variables. We used parametric survival models for risk prediction, because these models enable direct estimation of baseline hazard function as an absolute measure of effect. We first examined the underlying hazard function, which overall was monotonically decreasing from birth to 18 years, and compared models with different parametric survival distributions (exponential, Gompertz, and Weibull) using the Akaike information criterion and the Bayes information criterion. We then selected a Weibull proportional hazard regression model to develop a risk index for predicting the risk of death or a disability diagnosis up to 18 years of age. Only cases with complete information were analyzed. Maternal smoking was not included in model development because of considerable missing data. The clustered sandwich estimator was used to estimate the standard errors of coefficients, taking into account the clustering of births within mothers. All candidate variables except parity were found to be influential in the variable selection process using backward elimination at the 0.05 significance level, and thus were included in the final prediction model. The model provides coefficients for the "shape" parameter of the Weibull distribution, the constant term, and individual predictors. The probability of surviving by time t (years) is estimated by $S(t) = \exp [\, t^p [- \exp (a + b_1x_1 + b_2x_2 + \ldots + b_nx_n)]]$, where p is the Weibull shape parameter, a is the constant in the regression equation, and $[b_1,\ldots,b_n]$ are the coefficients for the covariates $[x_1,\ldots,x_n]$. The adjusted coefficients, corresponding hazard ratios (HRs), and 95% CIs are presented. All analyses were carried out in Stata 15.1 (StataCorp, College Station, Texas).

The study was reviewed and approved by the Western Australian Department of Health's Human Ethics Review Committee (2011/64) and the Western Australian Aboriginal Health Ethics Committee (613).

Results

A total of 720 901 infants were born live at a gestational age ≥22 weeks and birth weight ≥400 g between January 1983 and December 2010. Characteristics of these births are summarized in Table I. The majority of the mothers were aged 20-34 years inclusive (80.0%), Caucasian (85.4%), and married (89.4%) at the time of birth. Approximately two-fifths (40.3%) of the pregnant women were nulliparous, and nearly all pregnancies were singletons (97.2%). The majority of births occurred between 39 and 41 weeks of gestation (62.2%), with 8225 (1.1%) occurring at <32 weeks. The vast majority of newborns had a birth weight of ≥2500 g (93.9%) and a 5-minute Apgar score of 7-10 (98.4%).

Of the 720 901 newborns, 11 172 had a diagnosis of either intellectual disability or autism recorded in the IDEA database by December 2012, and 1663 (911 of whom were unique to the WA Cerebral Palsy Register) were diagnosed with cerebral palsy from the WARDA. As a result, a total of 12 083 children were diagnosed with disability (Table II). Of the 6008 children who died during the study period, 5662 died before being assigned a diagnosis of intellectual disability, autism, or cerebral palsy (Table II). The median age at diagnosis was 1 year for cerebral palsy, 3.8 years for autism, and 7.4 years for intellectual disability (Table II). A small number of infants not included in the Death Register but with a mode of separation code in the MNS data indicating death were coded as deceased for the purpose of this study.

The probability of survival to age 25 years free from disability was 4.1% for those born at 22 weeks of gestational age, 19.7% for those born at 23 weeks, 42.4% for those born at 24 weeks, 53.0% for those born at 25 weeks, 78.3% for those born at 28 weeks, and 97.2% for those born full term, at 39-41 weeks ($P < .01$, log-rank test) (Table III; available at www.jpeds.com). For births at <32 weeks, the probability of disability-free survival to 5 years improved over time from 70.8% (95% CI, 68.7%-72.8%) in 1980-1989 to 79.3% (95% CI, 77.8%-80.8%) in 1990-1999 and 81.9% (95% CI, 80.5%-83.2%) in 2000-2010 ($P < .01$). The disability-free survival for infants born <32 weeks also varied by sex (lower for males; $P < .01$), race (lower for Aboriginal infants; $P < .01$), maternal age (lower for younger mothers; $P < .01$), residence at birth (lower in remote areas; $P < .01$), and socioeconomic disadvantage (lower for those at greater socioeconomic disadvantage; $P < .01$).

The risk of death or intellectual disability was elevated in each gestational age category below 39-41 weeks, with pronounced effects in the extremely preterm period. The adjusted HR was 19.3 (95% CI, 14.5-24.6) for those born at 22-23 weeks and 3.7 for those born at 24-27 weeks (95% CI, 3.1-4.5), with a ratio of 1.2-1.5 at gestational age 28-38 weeks compared with 39-41 weeks (Table IV). The predicted likelihoods of disability-free survival up to 1, 2, and 5 years by selected gestational age groups, maternal ethnicity, and demographic/birth profiles are shown in Table V. According to the prediction model, the probability of disability-free survival up to 2 years was 0% and 0.1% for Aboriginal and Caucasian mother births, respectively, at 22-23 weeks gestation (profile 1: 5-minute Apgar score, 0-6; birth weight, 400-1499 g; parity, 2; IRSD, <10%; male sex; maternal marital status, never married; maternal age <20 years; birth year, 2000-2010; onset of labor/delivery method, spontaneous/vaginal; remoteness area, remote). In contrast, the probability of disability-free survival increased to 24.0% and 34.2%, respectively, when the following predictors were varied in profile 2: parity, 0; IRSD, ≥90%; female sex; maternal marital status, married;

Table I. Characteristics of the 720 901 live births in WA between January 1, 1983, and December 31, 2010

Characteristics	Value
Maternal characteristics	
Age at delivery, y	
Median (range; IQR)	28.9 (12.3-57.7; 25.0-32.8)
<20, n (%)	42 197 (5.9)
20-34, n (%)	577 077 (80.0)
>34, n (%)	101 626 (14.1)
Missing, n (%)	1 (0.0)
Ethnicity, n (%)	
Caucasian	615 279 (85.4)
Aboriginal/TSI	42 001 (5.8)
Other	63 621 (8.8)
Marital status, n (%)	
Married (incl. de facto)	644 657 (89.4)
Never married	66 171 (9.2)
Former or unknown	10 073 (1.4)
Smoking during pregnancy, n (%)	
No	295 060 (40.9)
Yes	65 025 (9.0)
Missing	360 816 (50.1)
Birth characteristics	
Number of previous births (parity)	
Median (range; IQR)	1 (0-17; 0-2)
0, n (%)	290 397 (40.3)
1, n (%)	240 707 (33.4)
2, n (%)	118 349 (16.4)
3, n (%)	43 996 (6.1)
4, n (%)	15 994 (2.2)
5+, n (%)	11 457 (1.6)
Missing, n (%)	1 (0.0)
Onset of labor/delivery method, n (%)	
Spontaneous/vaginal	374 278 (51.9)
Induced/vaginal	170 528 (23.7)
Elective cesarean delivery	96 056 (13.3)
Emergency cesarean delivery	80 039 (11.1)
Number of births, n (%)	
Single	700 861 (97.2)
Multiple (2-5)	20 040 (2.8)
Birth year, n (%)	
1983-1989	166 371 (23.1)
1990-1999	252 917 (35.1)
2000-2010	301 613 (41.8)
Gestational age, wk	
Median (range; IQR)	39 (22-46; 38-40)
22-23, n (%)	556 (0.1)
24-27, n (%)	2233 (0.3)
28-31, n (%)	5436 (0.8)
32-34, n (%)	14 231 (2.0)
35-36, n (%)	35 648 (4.9)
37-38, n (%)	202 795 (28.1)
39-41, n (%)	448 112 (62.2)
>41, n (%)	11 890 (1.7)
Sex, n (%)	
Male	369 626 (51.3)
Female	351 275 (48.7)
Birth weight, g	
Mean (SD)	3354 (571)
400-1499, n (%)	6987 (1.0)
1500-2499, n (%)	37 049 (5.1)
≥2500, n (%)	676 865 (93.9)
5-minute Apgar score, n (%)	
0-6	10 486 (1.5)
7-10	709 661 (98.4)
Missing	754 (0.1)
Remoteness area (ARIA), n (%)	
Major cities	467 735 (64.9)
Inner regional	65 656 (9.1)
Outer regional	62 539 (8.7)
Remote	32 876 (4.6)
Very remote	17 603 (2.4)
Missing	74 492 (10.3)
Socioeconomic status (IRSD), n (%)	
<10%	69 776 (9.7)
10-24%	109 472 (15.2)
25-49%	166 765 (23.1)
50-74%	154 463 (21.4)
75-89%	91 228 (12.7)
≥90%	52 770 (7.3)
Missing	76 427 (10.6)

ARIA, Accessibility/Remoteness Index of Australia; *TSI*, Torres Strait Islanders.

maternal age, 20-34 years; and remoteness, major cities. By further changing the 5-minute Apgar score to 7-10 in profile 3, the probability increased to 73.6% and 79.3%, respectively.

Discussion

Our study provides detailed estimates of the probability of survival without a diagnosis of intellectual disability, autism, or cerebral palsy for children born at ≥22 weeks of gestation in WA over the last 3 decades. This probability improved substantially with increasing gestational age and was influenced by perinatal and sociodemographic factors, with Aboriginal children and those born with lower Apgar scores at particularly elevated risk. Aboriginal infants have been shown to have poorer perinatal outcomes, often due to modifiable factors.[28] We also have shown that disability-free survival has increased in preterm babies born at 22-32 weeks gestation from 70% in the 1980s to >80% in 2000-2010.

The capacity to link information on antenatal and perinatal and sociodemographic circumstances from the WA MNS with WA Registry of Births, Deaths, and Marriages and the WARDA provided us with the ability to provide estimates not only of survival by gestational age, but also of the likelihood of intellectual disability, cerebral palsy, or autism. We were also able to combine these variables in a single model to provide an estimated likelihood of survival without a major disability. Moreover, the inclusion of variables identifiable at birth or before in our models allowed us to make these predictions in a timely manner for both clinicians and families.

After limiting our analysis to low birth weight spontaneous/vaginal births since 2000, 1-year survival for an Aboriginal infant born at 22-23 weeks gestation increased from 0.1% for infants with a high risk profile to 80.3% for at lower risk (female children born with a high Apgar score to nulliparous women aged 20-34 years who were married and living in major cities and higher sociodemographic areas). This differential is driven primarily by 5-minute Apgar score, with the predicted probability of disability-free survival increasing from 35.9% to 80.3% when the Apgar score changes from 0-6 to 7-10. These findings partly reflect the

Table II. Frequency distribution and time at risk of death or diagnosis with intellectual disability, autism, and cerebral palsy, by gestational age group

Gestational age, wk	Number	Deaths, n (%)	Disability diagnosis, n (%)				Death or disability diagnosis, n (%)	Time at risk (person-years)
			Overall	Autism*	ID only	CP†		
22-23	556	424 (76.3)	41 (7.4)	2 (0.4)	23 (4.1)	16 (2.9)	465 (83.6)	1061
24-27	2233	553 (24.8)	266 (11.9)	13 (0.6)	122 (5.5)	131 (5.9)	819 (36.7)	17 409
28-31	5436	291 (5.4)	376 (6.9)	12 (0.2)	159 (2.9)	205 (3.8)	667 (12.3)	63 342
32-34	14 231	346 (2.4)	499 (3.5)	66 (0.5)	320 (2.3)	113 (0.8)	845 (5.9)	173 000
35-36	35 648	439 (1.2)	921 (2.6)	128 (0.4)	656 (1.8)	137 (0.4)	1360 (3.8)	445 498
37-38	202 795	1203 (0.6)	3498 (1.7)	704 (0.4)	2443 (1.2)	351 (0.2)	4701 (2.3)	2 446 404
39-41	448 112	2290 (0.5)	6231 (1.4)	1321 (0.3)	4234 (0.9)	676 (0.2)	8521 (1.9)	6 133 081
>41	11 890	116 (1.0)	251 (2.1)	31 (0.3)	186 (1.6)	34 (0.3)	367 (3.1)	209 350
Overall	720 901	5662 (0.8)	12 083 (1.7)	2277 (0.3)	8143 (1.1)	1663 (0.2)	17 745 (2.5)	9 489 145
Median time to event (range; IQR)		2.8 mo (1 d to 27.9 y; 3 d to 3.5 y)	5.1 y (1 d to 24.8 y; 2.2 y to 9.7 y)	3.8 y (19 d to 20.3 y; 2.7 y to 5.9 y)	7.4 y (1 d to 24.8 y; 3.2 y to 11.0 y)	1 y (21 d to 20.4 y; 1 y to 1.8 y)	3.5 y (1 d to 27.9 y; 9 mo to 9.2 y)	

CP, cerebral palsy; *ID*, intellectual disability.
*With or without ID.
†With or without ID and/or autism.

relative disadvantage faced by Aboriginal Australians, but also further affirm that there is a dynamic relationship between socioeconomic circumstances and ethnic background in the shaping of early-life outcomes.[29]

Although many studies have examined either survival or cognitive outcomes in survivors by gestational age, few studies have examined both parameters in a single model. Studies reporting survival as the sole outcome have used different, usually shorter, follow-up periods. The large French EPIPAGE-2 study of preterm infants born at 22-34 weeks of gestation[19] restricted its analysis to survival to discharge. That study, undertaken in 2011, showed graphically that survival without severe morbidity varied from about 10% at 24 weeks to nearly 50% at 26 weeks and >70% at 28 weeks. On the other hand, a Californian population study[30] investigating extremely preterm infants found that survival to 1 year ranged from 6% at 22 weeks to 94% at 28 weeks—results that are broadly consistent with the findings of our present study. A UK study[31] examined the effects of regional variation and socioeconomic status on survival to discharge and to 28 days, and provided a prediction model that estimated the effect of various factors on survival. A US study[32] examined the effect of racial and ethnic differences on in-hospital mortality and other outcomes for preterm infants. Although there appeared to be a protective effect for black and Hispanic neonates in some outcomes, such as respiratory distress syndrome, there was no difference in in-hospital mortality. Another Korean study[33] investigated in-hospital mortality in infants born at 23-26 weeks of gestation. Along with examining trends over time, this study investigated the effects of delivery type, Apgar score, and use of antenatal steroids on mortality and found a protective effect not only of Apgar score, but also of antenatal steroid use, 1 of 4 recommended evidence-based practices,[34] on mortality overall and in those born at 25-26 weeks of gestation. Progress is now being made in the use of more advanced techniques, such as machine learning, to develop such prediction tools.[35]

All of the foregoing studies focused on survival over relatively short time frames and did not consider outcomes in later life among survivors. Other studies examined cognitive outcomes in survivors[14,17-19] but did not always include the full spectrum of gestational age or information on non-survivors. Indeed, a Swedish study investigating neurodevelopmental outcomes in a national cohort of extremely preterm survivors (<27 weeks) found a survival rate of 3.9% at in children born at 22 weeks of gestation and 57% in those born at 26 weeks.[17] Overall, of the surviving extremely preterm children, 31% had mild disability, 16% had moderate disability, and 11% had severe disability. Studies have also compared neurodevelopmental outcomes in very preterm (<32 weeks of gestation)[15] or extremely preterm (<27 weeks of gestation)[18] and term born controls in either an individual study[18] or in a meta-analysis,[15] with principal outcomes of a comparison of IQ scores between the 2 groups without taking other factors into account.

We have taken survival into account when describing the cognitive or disability outcomes in our cohort. Our findings

Table IV. Prognostic model and HRs for risk of death or diagnosis with intellectual disability, autism, and cerebral palsy (birth to 25 years) in live- born children in WA

Variables	n (column %)	Death or diagnosis, n (%)	Coefficient	Adjusted HR (95% CI)	*P* value
Gestational age, wk					
22-23	485 (0.1)	405 (83.5)	2.9581	19.3 (14.5-24.6)	<.01
24-27	1944 (0.3)	704 (36.1)	1.3147	3.7 (3.1-4.5)	<.01
28-31	4822 (0.8)	580 (12.0)	0.3728	1.5 (1.2-1.7)	<.01
32-34	12 675 (2.0)	741 (5.9)	0.2687	1.3 (1.2-1.5)	<.01
35-36	31 872 (5.0)	1197 (3.8)	0.3015	1.4 (1.3-1.5)	<.01
37-38	182 033 (28.3)	4155 (2.3)	0.1814	1.2 (1.2-1.2)	<.01
39-41	399 466 (62.1)	7455 (1.9)		Reference	
>41	10 266 (1.6)	300 (2.9)	0.1627	1.2 (1.0-1.3)	.01
5-min Apgar score					
0-6	9109 (1.4)	1800 (19.8)	1.5391	4.7 (4.4-5.0)	<.01
7-10	634 458 (98.6)	13 737 (2.2)		Reference	
Birth weight, g					
400-1499	6166 (1.0)	1647 (26.7)	1.4565	4.3 (3.6-5.1)	<.01
1500-2499	32 833 (5.1)	1894 (5.8)	0.7825	2.2 (2.0-2.4)	<.01
≥2500	604 568 (93.9)	11 996 (2.0)		Reference	
Previous births (parity)					
0	260 697 (40.5)	5844 (2.2)		Reference	
1	216 077 (33.6)	4612 (2.1)	0.0992	1.1. (1.1-1.2)	<.01
2	104 588 (16.3)	2682 (2.6)	0.2307	1.3 (1.2-1.3)	<.01
3	38 478 (6.0)	1279 (3.3)	0.3884	1.5 (1.4-1.6)	<.01
4	13 837 (2.2)	547 (4.0)	0.4793	1.6 (1.5-1.8)	<.01
5+	9890 (1.5)	573 (5.8)	0.7930	2.2 (2.0-2.5)	<.01
Socioeconomic status (IRSD), %					
<10	69 645 (10.8)	3023 (4.3)	0.7231	2.1 (1.9-2.3)	<.01
10-24	109 253 (17.0)	3236 (3.0)	0.5124	1.7 (1.5-1.8)	<.01
25-49	166 497 (25.9)	4034 (2.4)	0.4072	1.5 (1.4-1.6)	<.01
50-74	154 337 (24.0)	3052 (2.0)	0.2699	1.3 (1.2-1.4)	<.01
75-89	91 087 (14.2)	1429 (1.6)	0.0964	1.1 (1.0-1.2)	.04
≥90	52 748 (8.2)	763 (1.5)		Reference	
Sex					
Male	330 090 (51.3)	9915 (3.0)	0.5200	1.7 (1.6-1.7)	<.01
Female	313 477 (48.7)	5622 (1.8)		Reference	
Maternal marital status					
Married (including de facto)	575 521 (89.4)	12 700 (2.2)		Reference	
Never married	58 905 (9.2)	2459 (4.2)	0.3133	1.4 (1.3-1.5)	<.01
Former or unknown	9141 (1.4)	378 (4.1)	0.2939	1.3 (1.2-1.5)	<.01
Maternal ethnicity					
Caucasian	550 643 (85.6)	12 590 (2.3)		Reference	
Aboriginal/TSI	33 979 (5.3)	1914 (5.6)	0.2852	1.3 (1.2-1.4)	<.01
Other	58 945 (9.2)	1033 (1.8)	−0.1490	0.9 (0.8-0.9)	<.01
Maternal age at delivery, y					
<20	36 774 (5.7)	1514 (4.1)	0.2487	1.3 (1.2-1.4)	<.01
20-34	514 621 (80.0)	12 098 (2.4)		Reference	
>34	92 172 (14.3)	1925 (2.1)	−0.0318	1.0 (0.9-1.0)	.27
Birth year					
1983-1989	142 930 (22.2)	4623 (3.2)	0.0521	1.1 (1.0-1.1)	.04
1990-1999	225 053 (35.0)	6975 (3.1)	0.2123	1.2 (1.2-1.3)	<.01
2000-2010	275 584 (42.8)	3939 (1.4)		Reference	
Onset of labor/delivery method					
Spontaneous/vaginal	331 312 (51.5)	7883 (2.4)		Reference	
Induced/vaginal	152 642 (23.7)	3365 (2.2)	0.0836	1.1 (1.0-1.1)	<.01
Elective cesarean delivery	87 124 (13.5)	1882 (2.2)	0.1569	1.2 (1.1-1.2)	<.01
Emergency cesarean delivery	72 489 (11.3)	2407 (3.3)	0.1667	1.2 (1.1-1.2)	<.01
Remoteness area (ARIA)					
Major cities	466 353 (72.5)	10 774 (2.3)		Reference	
Inner regional	65 395 (10.2)	1523 (2.3)	−0.0694	0.9 (0.9-1.0)	.03
Outer regional	62 384 (9.7)	1681 (2.7)	−0.0293	1.0 (0.9-1.0)	.32
Remote	32 475 (5.1)	870 (2.7)	−0.0879	0.9 (0.8-1.0)	.03
Very remote	16 960 (2.6)	689 (4.1)	−0.0529	0.9 (0.9-1.0)	.31
Constant (a)	643 567	15 537 (2.4)	−6.2142		
Shape (p)	643 567		0.4793		

demonstrated that in WA, where there is 1 centralized tertiary obstetric and neonatal hospital with active intensive care offered from 23 weeks,[36] disability-free survival to 1 year was >20% for infants born at 22-23 weeks of gestation, >70% at those born at 26 weeks, and >80% in those born at 28 weeks. Similarly, a WA study based at this hospital[36] investigated survival free of moderate/severe disability (including deafness and blindness) at up to 5 years of age for extremely

Table V. Predicted probability of disability-free survival to 1, 2, and 5 years of age in Aboriginal and Caucasian maternal populations, by gestational age group and birth profile

	Predicted probability, %					
	1 y		2 y		5 y	
Profile/gestational age	Aboriginal	Caucasian	Aboriginal	Caucasian	Aboriginal	Caucasian
Profile 1						
22-23 wk	0.1	0.4	0	0.1	0	0
24-27 wk	24.9	35.2	14.4	23.3	4.9	10.4
28-31 wk	58.2	66.5	47.0	56.7	31.0	41.4
Profile 2						
22-23 wk	35.9	46.3	24.0	34.2	10.9	18.9
24-27 wk	82.0	86.2	75.9	81.2	65.1	72.5
28-31 wk	92.6	94.4	89.8	92.2	84.6	88.2
Profile 3						
22-23 wk	80.3	84.8	73.6	79.4	62.1	69.9
24-27 wk	95.8	96.9	94.2	95.6	91.2	93.3
28-31 wk	98.4	98.8	97.7	98.3	96.5	97.3

Profile 1: Apgar score, 0-6; birth weight, 400-1499 g; parity, 2; IRSD, <10%; male sex; maternal marital status, never married; maternal age, <20 years; birth year, 2000-2010; onset of labor/delivery method, spontaneous/vaginal; remoteness area, remote.
Profile 2: Apgar score, 0-6; birth weight, 400-1499 g; parity, 0; IRSD, ≥90%; parity, 0; female sex; maternal marital status, married; maternal age, 20-34 years; birth year, 2000-2010; onset of labor/delivery method, spontaneous/vaginal; remoteness area, major cities.
Profile 3: Apgar score, 7-10; birth weight, 400-1499 g; parity, 0; IRSD, ≥90%; parity, 0; female sex; maternal marital status, married; maternal age, 20-34 y; birth year, 2000-2010; onset of labor/delivery method, spontaneous/vaginal; remoteness area, major cities.
Underlined variables differ among the 3 profiles.

preterm infants. Although the authors did not report on disability-free survival, we extrapolated that 19.9% of those born at 22-23 weeks of gestation would have had this outcome. Comparisons between previous studies are difficult given the variation in the use of denominators related to live births or survivors, age at and type of developmental assessments, and inclusion or not of neurosensory impairments. Although others have limited their studies to specific preterm age groups,[14,17-19] our study used population-based databases to identify disability in the entire WA population and reported on all gestational age groups.

Our study has some limitations. It did not capture the milder and more common neurodevelopmental disorders, such as attention deficit hyperactivity disorder, because there are no available population registers to facilitate data linkage. Because we wanted to restrict our analysis to variables available at birth, this study did not specifically include information about neonatal morbidities, such as intraventricular hemorrhage or necrotizing enterocolitis or on whether active resuscitation was offered at birth.[37] We did not have information on the use of antenatal steroids.[37,38]

We believe that disability-free survival is an important concept. At birth and even before to birth when clinicians and families are making decisions about the viability and appropriateness of active resuscitation, not only survival, but also the likelihood of long-term major disability, need to be considered. ■

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Data Statement

Data sharing statement available at www.jpeds.com.

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Table III. Estimated probability of survival or free from diagnosis of intellectual disability, autism, or cerebral palsy at 1, 5, 10, 15, 20, and 25 years of age, by gestational age group

	Probability of survival, % (95% CI)					
Gestational age, (wk)	1 y	5 y	10 y	15 y	20 y	25 y
22	9.5 (6.1-13.8)	6.0 (3.3-9.7)	5.4 (2.9-9.1)	4.8 (2.4-8.4)	4.1 (1.9-7.6)	4.1 (1.9-7.6)
23	30.6 (25.7-35.6)	23.9 (19.4-28.7)	23.9 (19.4-28.7)	21.1 (16.2-26.5)	19.7 (14.5-25.5)	19.7 (14.5-25.5)
24	56.1 (51.3-60.7)	50.5 (45.6-55.2)	45.5 (40.3-50.5)	42.4 (36.9-47.8)	42.4 (36.9-47.8)	42.4 (36.9-47.8)
25	66.7 (62.3-70.7)	59.2 (54.6-63.5)	55.7 (50.9-60.2)	53.8 (48.8-58.5)	53.0 (47.9-57.9)	53.0 (47.9-57.9)
26	73.9 (70.3-77.1)	69.9 (66.1-73.4)	66.1 (62.0-69.8)	64.6 (60.4-68.4)	63.6 (59.2-67.6)	62.8 (58.2-67.0)
27	80.8 (77.6-83.7)	76.6 (73.1-79.7)	73.9 (70.1-77.3)	72.0 (68.0-75.6)	70.8 (66.6-74.5)	70.8 (66.6-74.5)
28	88.1 (85.8-90.0)	85.7 (83.2-87.8)	81.5 (78.6-84.0)	80.3 (77.3-82.9)	79.4 (76.2-82.1)	78.3 (74.7-81.3)
22-23	22.2 (18.8-25.7)	16.7 (13.6-20.0)	16.4 (13.3-19.7)	14.6 (11.4-18.1)	13.1 (9.8-16.9)	13.1 (9.8-16.9)
24-27	70.9 (68.9-72.7)	65.8 (63.7-67.7)	62.1 (60.0-64.2)	60.2 (57.9-62.4)	59.3 (57.0-61.6)	59.1 (56.7-61.4)
28-31	92.0 (91.2-92.7)	90.1 (89.3-90.9)	87.8 (86.8-88.7)	86.3 (85.3-87.3)	85.5 (84.4-86.5)	85.1 (83.9-86.2)
32-34	97.0 (96.7-97.2)	95.5 (95.2-95.9)	94.4 (94.0-94.8)	93.3 (92.8-93.7)	92.4 (91.8-92.9)	92.1 (91.4-92.6)
35-36	98.5 (98.4-98.6)	97.5 (97.3-97.7)	96.5 (96.2-96.7)	95.5 (95.3-95.8)	94.9 (94.6-95.2)	94.5 (94.1-94.8)
37-38	99.4 (99.3-99.4)	98.5 (98.5-98.6)	97.8 (97.7-97.8)	97.1 (97.0-97.2)	96.7 (96.6-96.8)	96.4 (96.3-96.5)
39-41	99.6 (99.6-99.6)	99.0 (98.9-99.0)	98.3 (98.3-98.4)	97.8 (97.8-97.9)	97.4 (97.4-97.5)	97.2 (97.1-97.3)
>41	99.3 (99.1-99.4)	98.7 (98.5-98.9)	98.0 (97.7-98.2)	97.1 (96.7-97.4)	96.5 (96.2-96.9)	96.2 (95.7-96.6)