

Ethical issues in the NICU and infant mortality

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Who gets admitted to the NICU

- Babies with acute illnesses
 - Sepsis
 - Hypoglycemia
 - Meconium aspiration
- Babies with congenital anomalies
 - Chromosomal – i.e. Trisomy 13, 18, 21
 - Congenital heart disease
 - myelomenigocele
- Premature babies

Acute illnesses

- No ethical dilemmas about initiating treatment
- Initiate treatment – succeed or fail
- Ethical issues arise with “partial success.”
 - Meningitis survivors with brain damage
 - Meconium aspiration survivors with chronic lung disease and vent dependence

Congenital anomalies

- Virtually all treatable and “compatible with life.”
- Ethical issues
 - “quality of life”
 - Trisomy 13 and 18
 - Anencephaly
 - burdens of treatment
 - Werdnig-Hoffman
 - Hypoplastic left heart syndrome

Consensus on quality of life

- Impermissible to stop treatment if similar to Trisomy 21 (Down's Syndrome)
- Permissible if similar to Trisomy 18
- Gray zone in between
- Decisions left to parents

Extremely premature babies

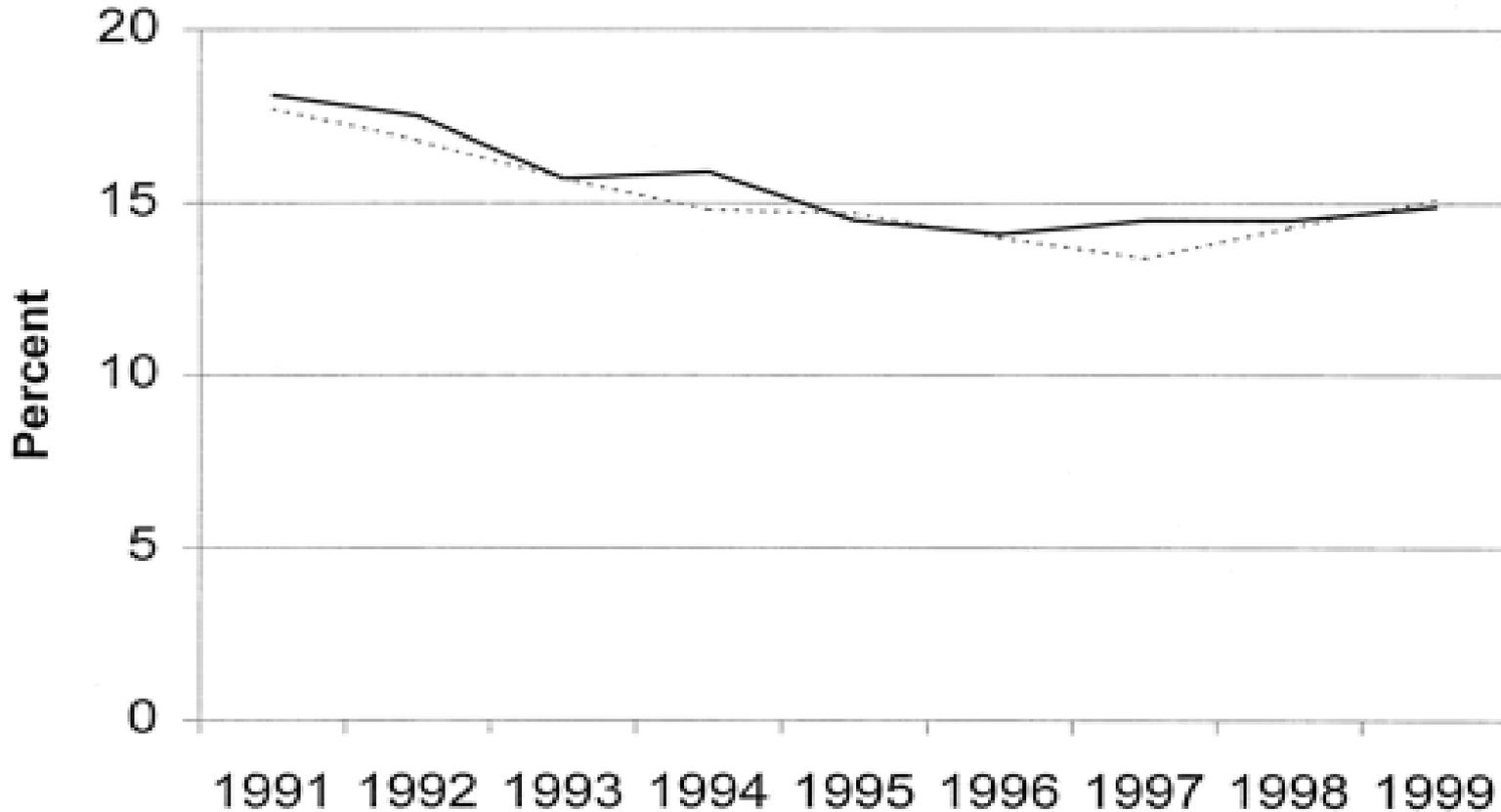
- Zone of uncertainty is narrow
- Treatment is generally considered obligatory for babies ≥ 25 weeks
- Treatment is “futile” for babies ≤ 22 weeks
- Zone of uncertainty is between 22-25 weeks, or, roughly, between 450 and 650 grams birthweight.

Table 4. Summary of Outcomes among Extremely Preterm Children.*

Outcome	22 Wk (N=138)	23 Wk (N=241)	24 Wk (N=382)	25 Wk (N=424)
	<i>number (percent)</i>			
Died in delivery room	116 (84)	110 (46)	84 (22)	67 (16)
Admitted to NICU	22 (16)	131 (54)	298 (78)	357 (84)
Died in NICU	20 (14)	105 (44)	198 (52)	171 (40)
Survived to discharge	2 (1)	26 (11)	100 (26)	186 (44)
Died after discharge	0	1 (0.4)	2 (0.5)	3 (0.7)
Lost to follow-up	0	3 (1)	25 (7)	39 (9)
At 6 yr of age				
Had severe disability	1 (0.7)	5 (2)	21 (5)	26 (6)
Had moderate disability	0	9 (4)	16 (4)	32 (8)
Had mild disability	1 (0.7)	5 (2)	26 (7)	51 (12)
Survived without impairment				
As a percentage of live births	0	3 (1)	10 (3)	35 (8)
As a percentage of NICU admissions	0	3 (2)	10 (3)	35 (10)
Survived without severe or moderate disability				
As a percentage of live births	1 (0.7)	8 (3)	36 (9)	86 (20)
As a percentage of NICU admissions	1 (5)	8 (6)	36 (12)	86 (24)

* NICU denotes neonatal intensive care unit.

Birthweight-specific mortality rates have stabilized since the mid 1990s



Mortality for infants 501 to 1500 g, 1991 to 1999,
at all 362 Vermont-Oxford network hospitals (solid line)
and at the 39 hospitals participating in all 9 years (dashed line).

Guidelines for Care of Extremely Preterm Infants

American Academy of Pediatrics/American Heart Association Neonatal Resuscitation Program, 2000

- Noninitiation of resuscitation in the delivery room is appropriate for newborns who have confirmed gestations of less than 23 weeks or birthweights of less than 400 g

Thames Regional Perinatal Group, 2000

- Less than or equal to 22 weeks' gestation: Compassionate care only
- 23 to 24 weeks' gestation: Resuscitation depends on infant's condition at birth
- 25 to 27 weeks' gestation: Full resuscitation and supportive care
-

Guidelines for Care of Extremely Preterm Infants

Canadian Pediatric Society, 1994

- 22 weeks' gestation: Treatment only at the request of fully informed parents.
- 23 to 24 weeks' gestation: There is a role for parental wishes.
- 25 weeks' gestation: Resuscitate unless infants have fatal anomalies

Colorado Collective for Medical Decisions, 2000

- 22 weeks' gestation: Comfort care is the only appropriate choice
- 23 weeks' gestation: advise comfort care, treat with informed consent.
- 24 weeks' gestation: collaborative process with good sharing of information.
- 25 weeks' gestation: Most participants were uncomfortable with withholding care.

What do doctors do in 2003?

- 500 surveys randomly sent to U.S. neonatologists with four DR scenarios:
 - BW < 500 g / gestational age (GA) 23 wks,
 - BW 500-600g / GA 24 wks,
 - BW 601-750g / GA 25 wks,
 - BW 751-1000g / GA 26 wks.
- Physician could choose: Full resuscitation, Comfort care, Parental preference, Other.
- **Results:**
 - At 23 weeks, 92% prefer comfort care.
 - At 24 weeks, 81% prefer resuscitation. 30% would defer to parental wishes.
 - At 25 weeks and greater, an overwhelming majority prefer full resuscitation. Few would defer to parents.

What do parents want?

- **Differences in Preferences for Neonatal Outcomes Among Health Care Professionals, Parents, and Adolescents.**
 - Saigal et al JAMA 1999
- 742 participants were interviewed between 1993 and 1995
 - 100 neonatologists from hospitals throughout Canada;
 - 103 neonatal nurses from 3 regional neonatal intensive care units;
 - 264 adolescents (12-16 years), including 140 who were ELBW infants and 124 sociodemographically matched term controls; and
 - 275 parents of the recruited adolescents.
- **Main Outcome Measure** Preferences (utilities) for 4 to 5 hypothetical health states of children were obtained by direct interviews using the standard gamble method.

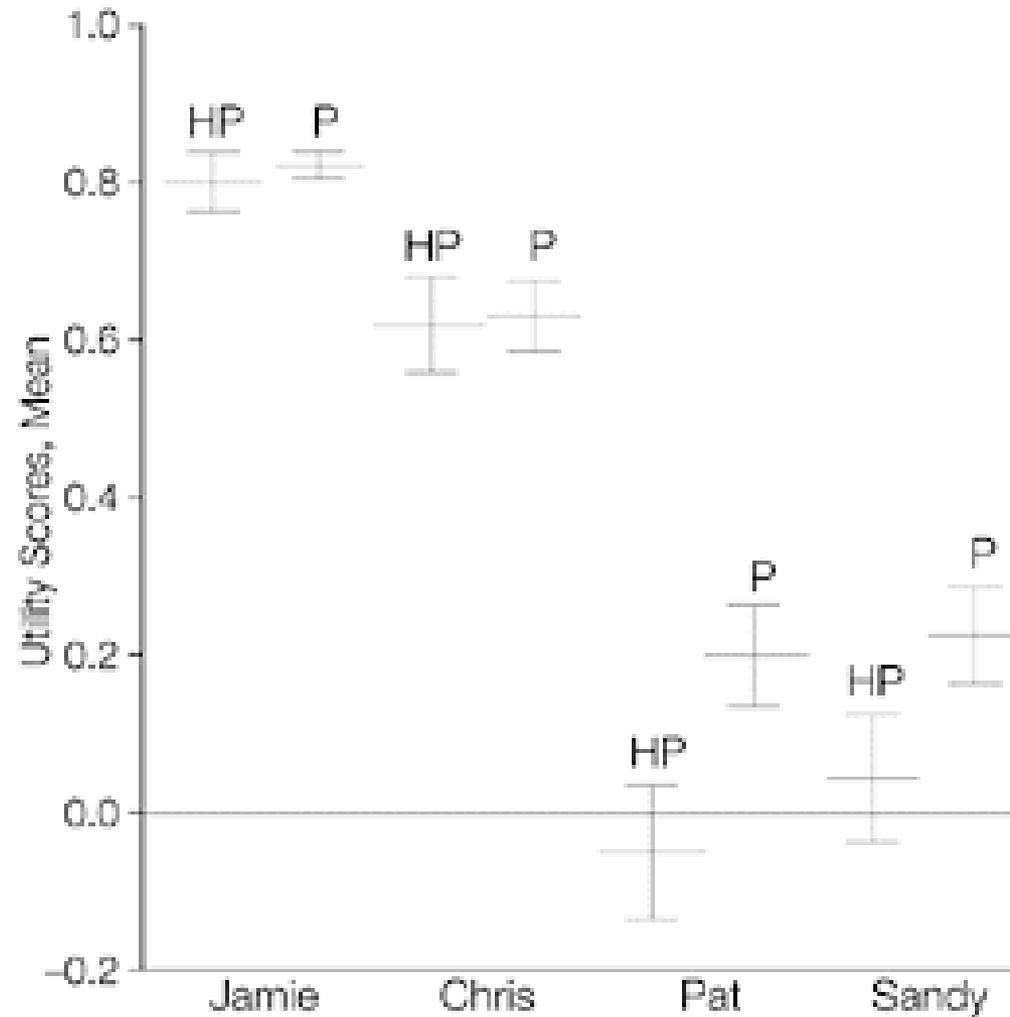
Four hypothetical children

- Jaimie – can see, hear, and talk normally, can walk, bend, lift, jump, and run normally, happy and not worried most of the time, learns and does schoolwork more slowly than the rest of the class, can eat, bathe, dress, and use the toilet normally, free of pain.
- Chris – can see, hear, and talk normally, needs equipment and the help of another person to walk, sometimes angry, worried or sad, can learn and do schoolwork without special help, can eat, bathe, dress, and use the toilet normally, free of pain

Four hypothetical children

- Sandy – has problems seeing, hearing, or talking, even with glasses and hearing aid, needs equipment to walk, sometimes angry, worried or sad, learns schoolwork very slowly and needs special help, needs special equipment to eat, bathe, dress or use the toilet, sometimes has pain that is relieved by Tylenol.
- Pat – blind, deaf, unable to talk, needs equipment to walk, happy and not worried most of the time, learns schoolwork very slowly and needs special help, needs help from another person to eat, bathe, dress or use the toilet, sometimes has pain that is relieved by Tylenol.

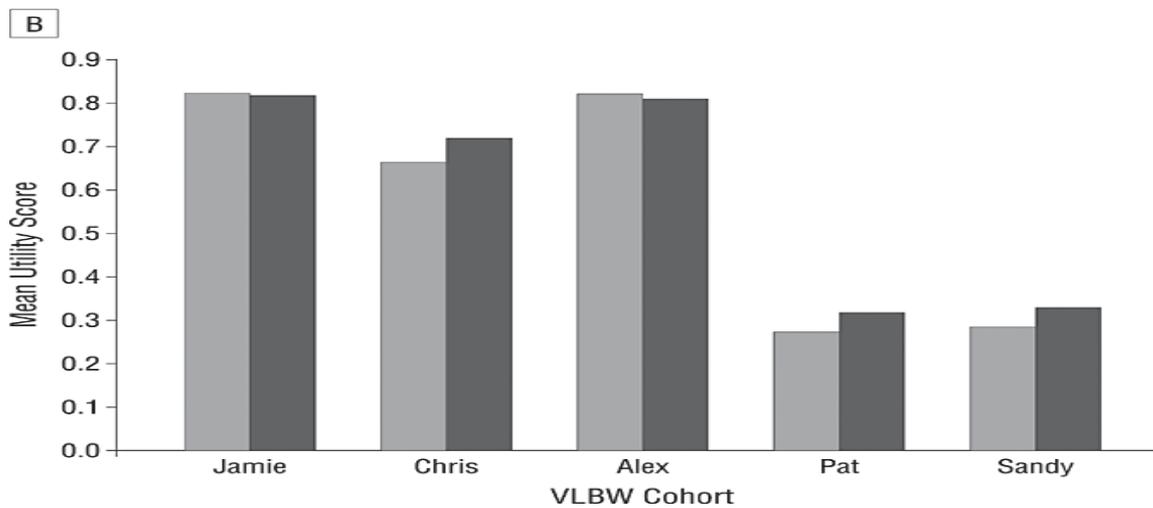
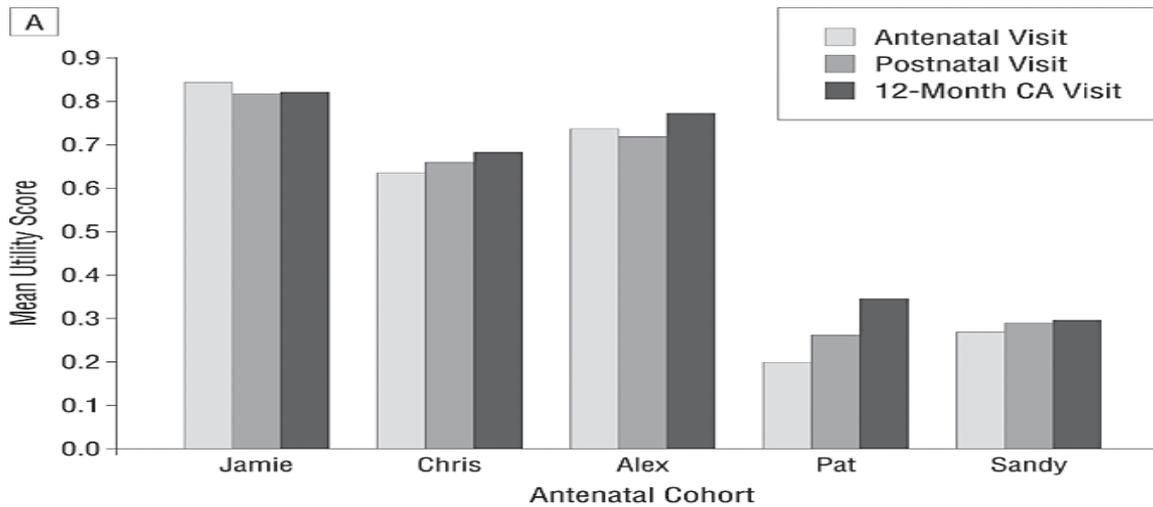
Comparison of Preferences of Health Care Professionals and Parents for 4 Hypothetical Health States



Saigal, S. et al. JAMA 1999;281:1991-1997.

What about pregnant women?

- 80 high-risk pregnant women recruited at 24 ± 2 weeks of gestation, and 75 mothers of VLBW infants recruited within 1 week of delivery.
- Opinions about five different case scenarios



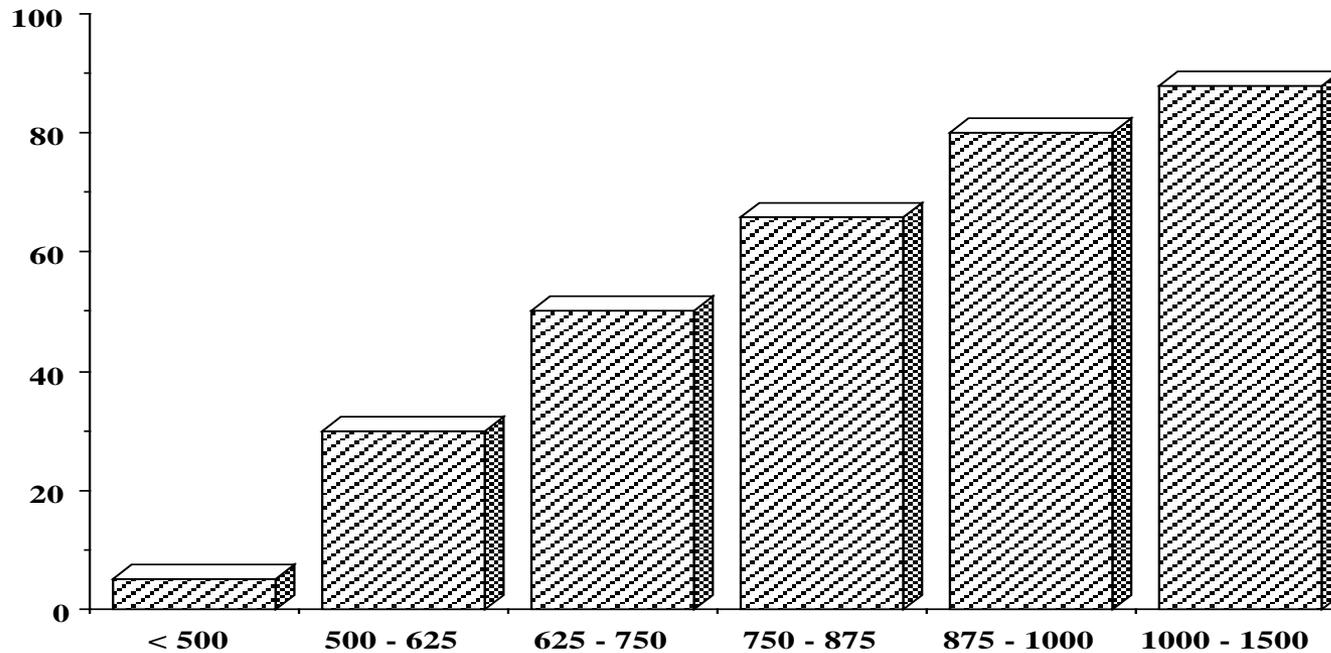
Saigal, S. et al. Arch Pediatr Adolesc Med 2003;157:261-269.

Conclusions of attitude surveys

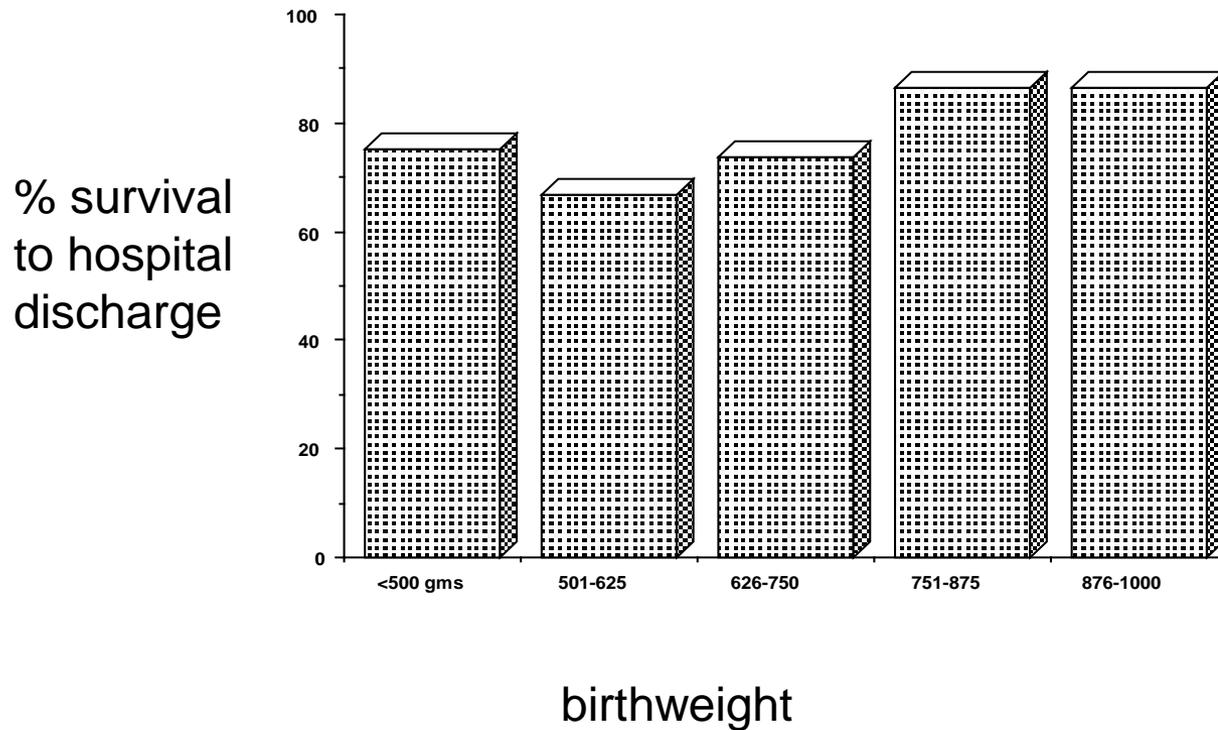
- Compared to parents, health professionals are more likely to rate some outcomes as “worse than death.”
- No survey looks at the “worst case scenario” of a child who is neurologically devastated.
- No survey takes prognostic uncertainty into account – all assume that one can predict outcomes with perfect accuracy.

What do we know about prognostic uncertainty

- It is hard to predict which babies are going to die.
- It is not so hard to predict which babies will either die or have significant neurological morbidity.
- Accurate predictions take time – babies “declare themselves.”



Survival to hospital discharge as a function of birth weight for 429 extremely low birth weight infants. Number of patients in each birth weight group: 400 to 500 g, n = 32; 501 to 625 g, n = 71; 626 to 750 g, n = 106; 751 to 875 g, n = 107; 876 to 1000 g, n = 110. (Meadow W, et al Pediatrics. 1996;97(5):636-43.)



Survival versus birth weight, restricted to extremely low birth weight infants alive on day of life 4. Number of patients in each birth weight group: 400 to 500 g, n = 4; 501 to 625 g, n = 24; 626 to 750 g, n = 57; 751 to 875 g, n = 74; 876 to 1000 g, n = 90. (Meadow W, Pediatrics. 1996;97(5):636-43.)

Percent
of babies
who died



Percentage of deaths as a function of day of life for 227 nonsurviving infants. (Meadow W, et al Pediatrics. 1996;97(5):636-43.)

“Crystal Ball” study: How good are we at predicting?

- 369 ventilated infants, 1996-97**
- SNAP scores on DOL 1, 3, 4, 5, 7, 10, 14, 21**
- Daily survey of nurses, residents, fellows, and attendings: "Do you think this child is going to live to go home to their family, or die before hospital discharge?"**

SNAP Values vs DOL for Surviving and Non-Surviving Infants

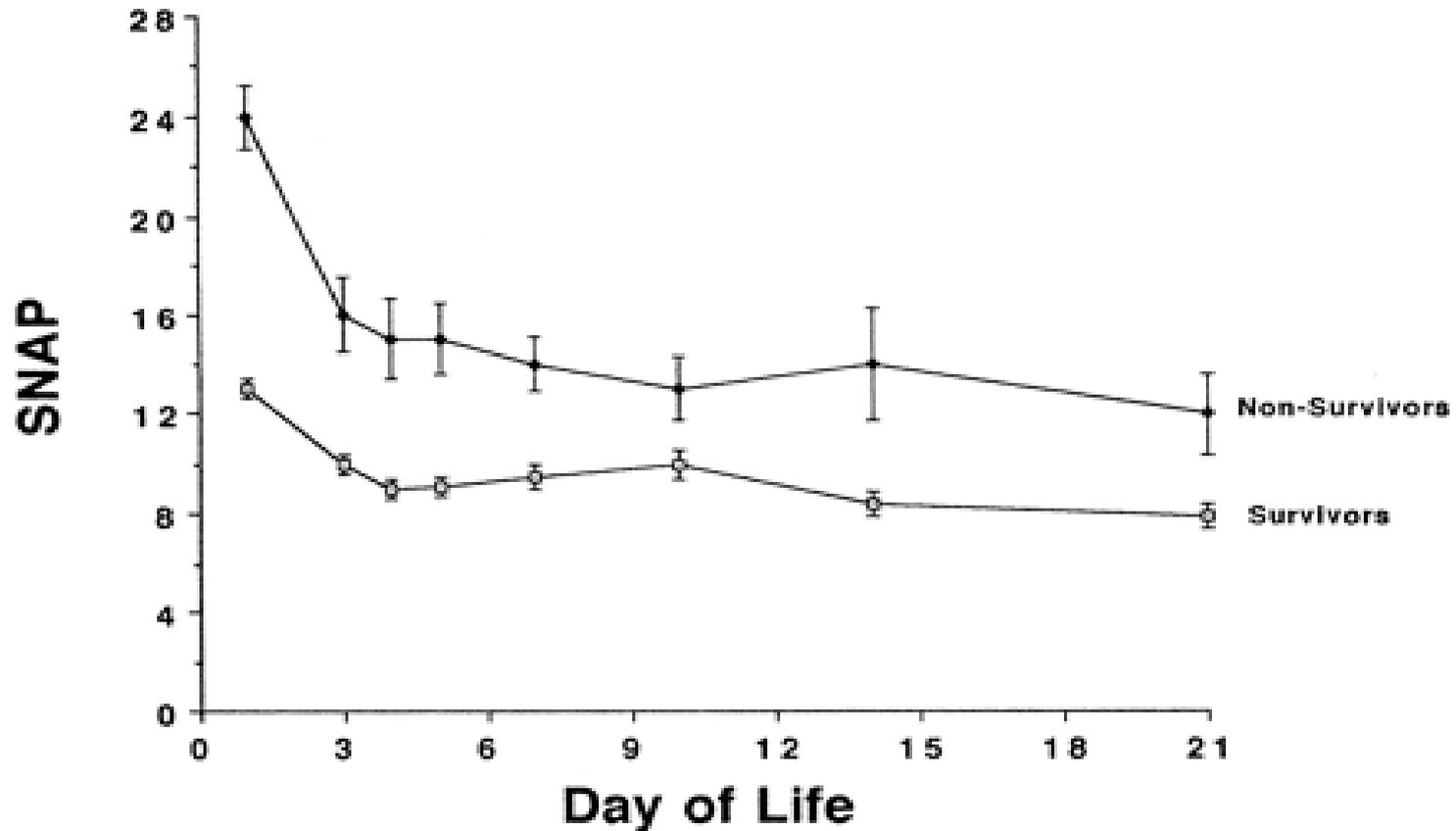


Fig 1. Average SNAP scores as a function of DOL for populations of survivors and nonsurvivors. On DOL 1, SNAP for nonsurvivors (24 ± 8.7 [SD]) was significantly higher than SNAP for survivors (13 ± 6.1 ; $P < .001$). This difference diminished steadily over time, as SNAP improved for both groups.

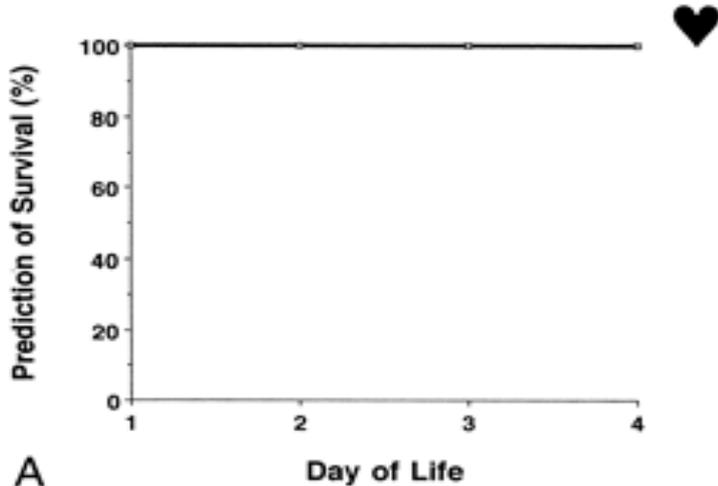
SNAP vs DOL for 285 Ventilated Infants



Fig 2. Scattergraph of every SNAP value obtained during the first 10 DOLs for 285 ventilated infants. 125 SNAP determinations for the 45 nonsurvivors and 696 SNAP values for 240 surviving infants are presented.

What about clinical intuitions?

Concordant, Correct Prediction of Survival

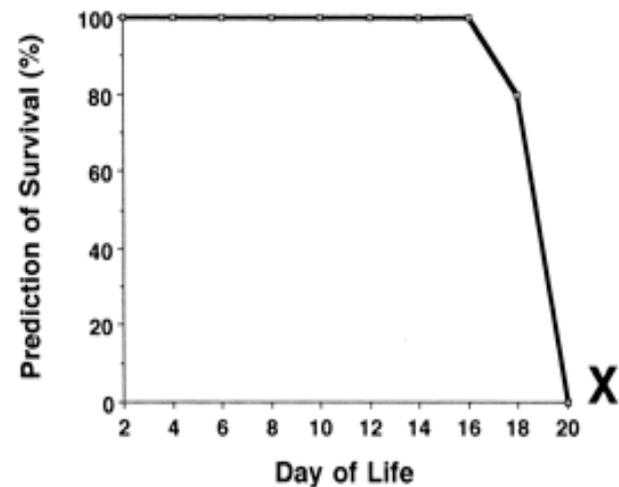


Concordant, Correct Prediction of Demise



A

Concordant, Incorrect Prediction of Survival



B

“Crystal Ball” Study

- Prediction of non-survival % wrong pt days
- At least one respondent 60% 505
- 50% of respondents 49% 328
- 100% of respondents 31% 140
- 3d of 100% agreement 18% 77

The crucial relationship between epidemiology and ethics

- Current consensus depends upon outcome statistics
- Current consensus depends upon the time it takes for babies to “declare themselves”
 - What if advances in therapy improve survival but also prolong dying?
 - What if babies stop “declaring themselves?”

Can the decision making process be improved? – A research agenda

- How much consistency or difference is there in the information that different neonatologists give parents?
 - Do they cite the same survival statistics?
 - How do they describe morbidity?
 - Do they use institution-specific data, national data, international data?
 - Do they adjust for the baby's race and gender?

Can the decision making process be improved? – A research agenda

- Do neonatologists use similar communication styles?
 - Do they listen?
 - Seek to empower parents?
 - Impose their agenda?
 - Allow different approaches with different families?

Can the decision making process be improved? – A research agenda

- Do parents and neonatologists differ because their values are different or because they have different information and understanding?
 - Compare studies of communication with retrospective assessments of satisfaction with the process?
 - Which parents regret the decisions they made? Why?