

# International Comparison of Care for Very Low Birth Weight Infants: Parents' Perceptions of Counseling and Decision-Making

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**ABSTRACT.** *Objective.* To characterize parent perceptions and satisfaction with physician counseling and delivery-room resuscitation of very low birth weight infants in countries with neonatal intensive care capacity.

*Study Design.* Convenience sample of 327 parents of 379 inborn very low birth weight infants (<1501 g) who had received resuscitation and neonatal intensive care in 9 neonatal intensive care units (NICUs) in 6 Pacific Rim countries and in 2 California hospitals. The sample comprised mostly parents whose infants survived, because in some centers interviews of parents of nonsurviving infants were culturally inappropriate. Of 359 survivors for whom outcome data were asked of parents, 29% were reported to have long-term sequelae. Half-hour structured interviews were performed, using trained interpreters as necessary, at an interval of 13.7 months after the infant's birth. We compared responses to interview questions that detailed counseling patterns, factors taken into consideration in decisions, and acceptance of parental decision-making.

*Results.* Parents' recall of perinatal counseling differed among centers. The majority of parents assessed physician counseling on morbidity and mortality as adequate in most, but not all, centers. They less commonly perceived discussions of other issues as adequate to their needs. The majority (>65%) of parents in all centers felt that they understood their infant's prognosis after physician counseling. The proportion of parents who expected long-term sequelae in their infant varied from 15% (in Kuala Lumpur, Malaysia) to 64% (in Singapore). The majority (>70%) of parents in all centers, however, perceived their infant's outcome to be better than they

expected from physician counseling. A majority of parents across all centers feared that their infant would die in the NICU, and approximately one third continued to fear that their infant might die at home after nursery discharge. The parents' regard for physicians' and, to a lesser extent, partners' opinions was important in decision-making. Less than one quarter of parents perceived that physicians had made actual life-support decisions on their own except in Melbourne, Australia, and Tokyo, Japan (where 74% and 45% of parents, respectively, reported sole physician decision-making). Parents would have preferred to play a more active, but not autonomous, role in decisions made for their infants. Counseling may heighten parents' anxiety during and after their infant's hospitalization, but that does not diminish their recalled satisfaction with counseling and the decision-making process.

*Conclusions.* Counseling differs by center among these centers in Australasia and California. Given that parents desire to play an active role in decision-making for their premature infant, physicians should strive to provide parents the medical information critical for informed decision-making. Given that parents do not seek sole decision-making capacity, physicians should foster parental involvement in life-support decisions to the extent appropriate for local cultural norms. *Pediatrics* 2005; 116:e263–e271. URL: [www.pediatrics.org/cgi/doi/10.1542/peds.2004-2274](http://www.pediatrics.org/cgi/doi/10.1542/peds.2004-2274); *resuscitation, very low birth weight, attitudes, decision-making, parent counseling, neonatal intensive care.*

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ABBREVIATION. VLBW, very low birth weight.

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Technological advances in neonatal intensive care have markedly improved survival of very premature infants in North America, Europe, Australia, and Asia.<sup>1–9</sup> Although representing a small proportion of births, very low birth weight (VLBW) infants impose a heavy emotional toll on their parents.<sup>10–12</sup> The costs of neonatal intensive care unit (NICU) and follow-up care for impaired survivors impose financial burdens on their families and compete with other important national health care priorities.<sup>13–21</sup> Worldwide, an array of challenging ethical, moral, legal, social, and religious considerations complicate decisions about neonatal intensive care for VLBW infants.<sup>22–27</sup>

Studies in several countries have characterized physician attitudes on life-sustaining therapies and providers' willingness to accept a parental voice in life-support decisions for extreme prematurity.<sup>19,28–38</sup>

In the emotional and often emergent milieu of the NICU, physician counseling may not suffice to help parents understand medical information necessary to engage them as active and informed participants in life-support decisions.<sup>37,39–41</sup> We recently reported that parents in public hospitals in South Africa wanted more consistent counseling and a larger stake in decision-making.<sup>42</sup> However, little international data are available to characterize differences in perinatal counseling and decision-making by physicians and parents of premature infants in different cultures. As a way to understand international differences and similarities in perinatal counseling and decision-making regarding resuscitation and life support for premature infants, we compared parents' experiences of care for their VLBW infants in medical centers in 6 Pacific Rim countries and in California.

## METHODS

### Study Sites

The Pacific Rim Neonatal Network was developed to study life-support decisions in NICUs in 9 participating centers in 6 countries (Australia, Hong Kong, Japan, Malaysia, Taiwan, and Singapore) in comparison to 2 university hospitals in San Francisco, California. Each participating hospital is capable of providing tertiary care for sick VLBW infants, and each maintains a computerized neonatal database containing detailed morbidity and mortality statistics. Perinatal counseling and resuscitation practices were not knowingly changed during this study.

### Procedures

From computer databases, investigators at each center identified parents whose VLBW infants were born and received care in their nurseries. Potential study subjects (parents) were notified by site directors by mail or telephone and asked if they would be interested in participating. Interested parents were scheduled for half-hour interviews done face to face at participating hospitals or by telephone when they could not return for an interview. All parents who volunteered to be interviewed were again provided information on the study purpose and questions before they signed written consent to be interviewed; none of the scheduled parents opted out. The resulting sample included mostly parents of inborn surviving infants; parents of nonsurviving infants were interviewed only in centers in which cultural taboos about death were less prevalent. The interviews were performed at a mean interval of 13.7 months after the infant's birth for the entire cohort (range: from 8.2 months in Kuala Lumpur, Malaysia, to 18.8 months in San Francisco).

Originally tested in parent interviews in California, the interview tool was well received in all centers. After their interviews, several parents stated after the interview that they appreciated the opportunity to relate their experiences; however, 1 parent who refused enrollment did request that we not contact her in the future. For this international comparison, each Pacific Rim site director reviewed the interview tool for clarity and local cultural relevance. The interview tool was translated into Chinese, Malay, and Japanese. Each translated interview tool was translated back into English to ensure identical content.

The interview tool included general demographic information on parents and health status on infant survivors. In each interview, we informed parents of our definition of "physician counseling" as those conversations in which medical providers discussed fetal or neonatal medical conditions or prognosis and potential or imminent decisions about life support that their infant might receive. The interview tool (an abbreviated questionnaire is included in the Appendix) asked parents about physician counseling, parents' attitudes about the effectiveness of counseling received during their infant's care, and parents' perceptions of the decision-making role for both the extent and direction of their infant's care. Additionally, we asked parents questions regarding their attitudes on the optimal locus of decision-making between physicians and parents, overall satisfaction with counseling and the decision-making process, and their suggestions for improving

the overall NICU experience. Questions about outcome status were deleted for the parents of nonsurviving infants. The interview concluded with an open-ended question on nursery experiences; these responses are not reported here.

Study personnel (J.C.P. and A.M.M.) interviewed parents from December 1998 through August 1999. Interviews were conducted using trained bilingual native speakers as interpreters when parents preferred. Interpreters were usually medically sophisticated (medical students, fellows, nurses, or physicians). Interviews lasted ~30 to 45 minutes depending on the need for translation and parents' open-ended comments about nursery experiences.

Counseling and decision-making variables were analyzed by pregnancy; for multiple-gestation pregnancies, infant variables and outcome status were recorded separately for each infant. Responses regarding perinatal counseling experiences and attitudes were yes/no responses or were ranked by using Likert scales for degree of agreement ("very," "somewhat," or "not"; or "very satisfied," "satisfied," "somewhat satisfied," or "not satisfied"). For this report, we collapsed the Likert scale responses into 2 groups ("yes" for "very satisfied"/"satisfied" or "always"/"usually" and "no" for "not satisfied" or "rarely"/"never").

### Sample

Demographic characteristics of interviewed parents and their neonates are presented in Table 1. This cohort of parents included 379 VLBW inborn infants (birth weight <1501 g) from 327 pregnancies, of which 54 were of multiple gestation. Because we have reported previously that outcome statistics in several of these centers were comparable to outcomes in the United States, we did not interview parents of infants born at  $\geq 1501$  g.<sup>43</sup> We did not set a lower birth weight or gestational age limit, because the thresholds for resuscitation were unknown at the time. (We have subsequently reported birth weight and gestational age thresholds for resuscitation elsewhere.<sup>44</sup>) The San Francisco cohort had lower birth weights, and the Taiwan cohort had larger birth weights in comparison to the other cohorts ( $P < .001$ ). The Taiwan cohort also had higher gestational ages than the Singapore and San Francisco cohorts ( $P < .001$ ). There were no differences between the Hong Kong, Singapore, Kuala Lumpur, and Melbourne, Australia, centers in length of stay; this information was not available for the Taiwan and San Francisco cohorts. Maternal education did not differ among the 7 countries. Data on maternal parity and religion were not collected routinely enough across centers to allow comparisons.

Of this cohort, 367 infants survived to nursery discharge; 12 died during the NICU admission. Stillborn fetuses ( $n = 4$ ) from the 327 pregnancies were not included in this report. Of the 359 survivors for whom outcome information was asked, 104 (29%) were perceived by their parents as having significant long-term complications as defined by (1) medical treatment for chronic lung disease, (2) neurodevelopmental disability after intraventricular hemorrhage, periventricular leukomalacia, asphyxia, or hydrocephalus, (3) residual visual deficits after retinopathy of prematurity, (4) treated hearing deficits, or (5) recurrent hospital admissions for treatment of medical complications from neonatal diseases.

### Statistical Analysis

We used Epistat 5.3 (Richardson, TX) to derive descriptive statistics (frequencies) and subgroup comparisons from survey responses. Differences between sites or subgroup responses were tested by using Pearson's  $\chi^2$  test for categorical data and the Mann-Whitney  $U$  test for ordinal variables except as noted.

## RESULTS

### Physician Counseling

Table 2 shows the proportion of parents reporting they felt that physicians' antenatal counseling was adequate and had addressed their needs. In most centers, a substantial proportion of parents recalled that physicians adequately discussed the possibility that their infant would die or be disabled. Differing proportions of parents recalled their physicians discussing bonding and attachment or pain and suffer-

**TABLE 1.** Study Sample Characteristics: Demographics of Parents and Their VLBW Infants

	Taiwan	Hong Kong	Singapore	Kuala Lumpur	Tokyo	Melbourne	San Francisco
Parents							
No. interviewed	45	42	56	37	31	51	65
Mean maternal age, y	†	32.5	31.7	31.1	34.5	31.1	31.7
Infants							
Mean chronologic age at interview, wk	75.2	56.5	41.5	36.9	70.5	53.4	85.8
VLBW infants (<1501 g), <i>n</i>	61	51	58	42	34	57	76
Mean birth weight, g (range)	1244 (710–1500)	1080 (468–1500)	1037 (510–1490)	1234 (600–1500)	1098 (642–1496)	1056 (546–1500)	1023 (567–1480)
Mean gestational age, wk	30.1	29.0	28.1	30.2	29.1	29.2	28.1
Stillborn infants and neonatal deaths, <i>n</i>	*	*	2	4	*	3	7
Mean length of stay, wk	†	12.5	12.2	10.6	†	12.3	†
Infants with reported sequelae, <i>n</i>	22/57	13/51	15/56	9/38	11/34	16/54	13/69

\* Parents of an infant who died were not eligible for interviews (see "Discussion").

† The question was not asked in some interviews.

ing, and overall, these topics were discussed less adequately than death or disability. Even lower proportions of parents, with wide differences by country, recalled their physician's discussion of financial issues or religious beliefs as adequate to their needs. In Tokyo, Japan, and Melbourne, <50% of parents felt that physicians had adequately discussed death; however, Melbourne was the only site in which a minority of parents felt that disability among survivors had been discussed adequately. In Tokyo and Melbourne, pain was less often recalled as adequately discussed by parents. Bonding and attachment were recalled as being discussed less adequately by parents in Melbourne. Adequate discussion of financial concerns was less common overall, most frequently in Tokyo (65%) and least frequently in Melbourne (4%). Across all centers, parents much less frequently recalled physician counseling in regard to religious beliefs as adequate (the highest was at 30% in Singapore and Kuala Lumpur, in the 2 countries with the largest religious diversity among the population).

The majority of parents counseled in all centers (from 68% in Tokyo to 90% in San Francisco) reported that they felt they understood the prognosis for their child (Table 3). The proportion of parents who expected their infant to have serious sequelae varied widely from a high of 64% in Singapore to a low of 15% in Kuala Lumpur. However, a large majority of parents in all centers felt that their infant's outcome was better than they had expected after antenatal counseling by their physician. A majority of parents in each center feared that their infant might die while in the nursery. Approximately one third continued to fear that their infant might die at home after nursery discharge except in Hong Kong and Tokyo, where <20% of parents feared this.

### Decision-Making

The majority of parents considered their emotional attachment, risks of death or disability and pain, and, to a lesser extent, financial and religious concerns in their delivery-room resuscitation decisions (Table 4). In all centers, a large majority of parents reported that they listened to physicians' and partners' opinions. In each of the centers, a larger proportion of parents took physicians' opinions into consideration than those who considered their partner's opinion. Parents in Tokyo less commonly reported considering their partner's opinion, death, disability, or pain and suffering compared with other centers. Parents in Taiwan were the least likely to consider potential disability in their decisions. There was more variation by center in the proportion of parents considering financial issues and religion than other factors in making resuscitation and life-support decisions. More parents in Singapore and Kuala Lumpur considered financial and religious issues relevant to resuscitation decisions than in other centers.

### Decision-Making Roles

Parents' perception of the process by which actual life-support decisions had been made during the infant's hospitalization varied widely by center (Table

**TABLE 2.** Adequacy of Perinatal Counseling as Reported by Parents

	Taiwan	Hong Kong (n = 42)	Singapore (n = 55)	Kuala Lumpur (n = 36)	Tokyo (n = 31)	Melbourne (n = 48)	San Francisco (n = 63)
Likelihood of death	*	62 (57, 66)	69 (57, 82)	70 (62, 79)	39 (33, 44)	46 (44, 48)	60 (57, 64)
Likelihood of disability	*	69 (62, 77)	69 (61, 77)	59 (55, 64)	61 (56, 67)	46 (44, 48)	73 (66, 81)
Pain and suffering	*	56 (54, 58)	44 (43, 45)	59 (55, 64)	29 (19, 39)	24 (14, 34)	44 (43, 46)
Attachment/bonding	*	54 (52, 55)	57 (54, 59)	59 (55, 64)	52 (51, 52)	22 (11, 33)	54 (53, 55)
Financial issues	*	29 (21, 37)	49 (49, 49)	49 (48, 49)	65 (58, 71)	4 (0, 22)	20 (11, 30)
Religious considerations	*	10 (0, 25)	30 (24, 37)	30 (21, 38)	4 (0, 25)	0	16 (5, 27)

Data are shown as percent (95% confidence interval).

\* The question was not asked in some interviews.

**TABLE 3.** Parents' Expectations After Antenatal Counseling

	Taiwan (n = 45)	Hong Kong (n = 42)	Singapore (n = 55)	Kuala Lumpur (n = 36)	Tokyo (n = 31)	Melbourne (n = 48)	San Francisco (n = 63)
Understood prognosis	70 (62, 77)	73 (63, 83)	81 (69, 93)	65 (59, 71)	68 (60, 77)	69 (26, 39)	90 (77, 100)
Expected sequelae	50 (50, 50)	38 (34, 42)	64 (59, 69)	15 (0, 30)	*	40 (37, 43)	45 (44, 47)
Sequelae better than parents expected	79 (68, 90)	80 (69, 92)	85 (73, 98)	83 (69, 98)	*	74 (65, 84)	97 (82, 100)
Feared death in NICU	*	57 (53, 60)	78 (68, 88)	70 (62, 79)	58 (54, 62)	71 (64, 79)	64 (59, 68)
Feared death at home	33 (27, 38)	15 (3, 27)	38 (34, 42)	39 (34, 44)	17 (2, 32)	33 (26, 39)	29 (23, 36)

Data are shown as percent (95% confidence interval).

\* The question was not asked in some interviews.

**TABLE 4.** Factors Considered by Parents in Decisions About Resuscitation Status for VLBW Infants

	Taiwan (n = 45)	Hong Kong (n = 42)	Singapore (n = 55)	Kuala Lumpur (n = 36)	Tokyo (n = 31)	Melbourne (n = 48)	San Francisco (n = 63)
Physician's opinion	93 (78, 100)	96 (79, 100)	94 (77, 100)	95 (76, 100)	100 (76, 100)	96 (78, 100)	94 (79, 100)
Partner's opinion	*	90 (75, 100)	87 (73, 100)	81 (68, 94)	63 (57, 69)	92 (76, 100)	87 (75, 99)
Attachment/bonding	*	82 (46, 100)	85 (72, 99)	84 (69, 98)	64 (58, 71)	84 (71, 97)	94 (80, 100)
Likelihood of death	70 (62, 77)	76 (66, 86)	81 (69, 94)	86 (71, 100)	43 (40, 46)	80 (68, 91)	73 (66, 81)
Likelihood of disability	39 (35, 43)	75 (65, 85)	78 (67, 88)	78 (66, 91)	52 (51, 52)	76 (66, 85)	63 (58, 66)
Pain and suffering	*	63 (58, 69)	85 (72, 88)	78 (66, 91)	55 (53, 57)	71 (63, 80)	89 (76, 100)
Financial issues	17 (5, 30)	27 (19, 36)	65 (59, 71)	73 (63, 83)	23 (11, 36)	6 (0, 23)	16 (5, 27)
Religious considerations	22 (11, 33)	25 (15, 35)	52 (51, 53)	54 (52, 56)	8 (0, 28)	18 (6, 31)	30 (24, 37)

Data are shown as percent (95% confidence interval).

\* The question was not asked in some interviews.

**TABLE 5.** Parents' Perceptions of Decision-Making Roles for Actual Resuscitation Decisions for VLBW Infants and Their Preference for an "Optimal" Decision-Making Process

	Taiwan (n = 45)	Hong Kong (n = 42)	Singapore (n = 55)	Kuala Lumpur (n = 36)	Tokyo (n = 31)	Melbourne (n = 48)	San Francisco (n = 37)
Perceived process in actual decisions							
Physician made decision alone	*	12	20	14	45	74	20
Joint decision-making between physician and parents	*	85	76	86	55	22	75
Parents made decision alone	*	4	2	0	0	4	5
Preferred roles for optimal decision-making process							
Physician should make decisions	54	15	35	11	*	14	14
Joint decision-making	84	92	81	95	*	78	62
Parents should listen to physician	85	91	96	89	*	90	95
Physician should listen to parents	20	45	35	27	*	44	57
Parents should make decisions	46	51	57	57	*	22	30

Data shown are percentages.

\* The question was not asked in some interviews.

5). In Melbourne, a large majority of parents (74%) perceived that physicians made decisions alone, whereas almost half of the parents felt so in Tokyo. In the other centers, less than one quarter of parents perceived that physicians had made decisions without parental input. In all centers, parents rarely felt that they alone had made decisions regarding the initial resuscitation status for their fetus. There was

more sole parental decision-making for smaller infants (<1000 g) than for larger ( $\geq 1000$  g) VLBW infants (6% vs <1%) and slightly more sole physician decision-making for larger than for smaller VLBW infants (32% vs 29%); there were no differences in shared decision-making by parents of larger versus smaller VLBW infants (65% vs 67%; log-likelihood ratio: 6.68;  $P = .04$ ).

**TABLE 6.** Parents' Satisfaction With the NICU Experience and Suggestions for Improvements

	Taiwan (n = 50)	Hong Kong (n = 48)	Singapore (n = 55)	Kuala Lumpur (n = 34)	Tokyo (n = 17)	Melbourne (n = 48)	San Francisco (n = 64)
<b>Satisfaction</b>							
Physician counseling	80 (68, 92)	91 (75, 100)	93 (77, 100)	97 (77, 100)	90 (71, 100)	74 (65, 83)	84 (73, 95)
Nursing involvement	93 (77, 100)	96 (79, 100)	91 (76, 100)	78 (66, 91)	87 (70, 100)	80 (68, 92)	89 (77, 100)
Written information	61 (57, 65)	53 (52, 54)	42 (-, -)	38 (33, 43)	35 (29, 42)	42 (38, 44)	73 (66, 80)
<b>Suggested improvements</b>							
More physician counseling	78 (67, 89)	94 (77, 100)	89 (74, 100)	97 (77, 100)	58 (54, 62)	71 (63, 80)	55 (53, 56)
More nursing involvement	61 (57, 65)	87 (73, 100)	75 (64, 85)	89 (72, 100)	19 (5, 34)	32 (25, 39)	23 (15, 32)
Use of primary language	70 (62, 77)	61 (57, 65)	56 (51, 62)	81 (68, 94)	3 (7, 23)	10 (0, 26)	17 (6, 27)
Use of simpler terminology	67 (61, 74)	81 (69, 93)	87 (73, 100)	89 (72, 100)	45 (43, 47)	40 (36, 44)	25 (17, 33)
More data on outcomes	87 (73, 100)	91 (75, 100)	93 (77, 100)	97 (77, 100)	71 (61, 81)	67 (61, 74)	34 (29, 39)

\* Data are shown as percent (95% confidence interval).

As to how resuscitation decisions ought to be made, Taiwan and Singapore stood out as the centers in which a substantial proportion of parents (54% and 35%, respectively) felt that physicians should optimally make resuscitation decisions without parental involvement. In other centers, a small proportion of parents ( $\leq 20\%$ ) felt that physicians should optimally make resuscitation decisions alone. Centers differed widely in the degree to which parents felt that physicians should listen to the parents. In all centers, joint decision-making was strongly preferred over sole physician or sole parental decision-making. A minority of parents in Taiwan, Melbourne, and San Francisco felt that they should make the decisions themselves.

Table 6 presents parents' overall satisfaction with the perinatal counseling that they received during their infant's hospitalization, as well as their suggestions for improvements to NICU counseling. A large majority of the parents expressed overall satisfaction with the perinatal counseling that they received from physicians and with nursing involvement in their infant's care. However, a large proportion of parents still suggested significant improvements in regard to perinatal counseling and decision-making: more physician and nursing time for information transfer, availability of information from interpreters, use of simpler terminology, and more information on potential outcomes for their child.

As a way to examine associations for infants most likely to have had substantial discussions about non-intervention, we compared the 128 infants with birth weights of  $< 1000$  g to the 199 infants with birth weights of  $\geq 1000$  g. Parents of smaller VLBW infants were more likely than parents of larger VLBW infants to have expected sequelae (62% vs 39%;  $P < .005$ ) and perceive their infant's outcome as abnormal (37% vs 24%;  $P < .005$ ). The smaller and larger birth weight subgroups did not differ in parents' fears of death in the NICU or at home, perceived outcome compared with expectations, or satisfaction with outcome.

## DISCUSSION

Although several hospital-based studies and surveys have detailed physicians' attitudes and practices on life support and end-of-life decisions for premature infants,<sup>19,29,30,33-36,45,46</sup> only a few have addressed parents' perspectives of counseling and

decision-making.<sup>42,45,47</sup> To our knowledge, this is the first cross-cultural study of counseling and resuscitation decision-making from the perspective of parents of VLBW premature infants.

## Counseling

Although outcomes of extremely low birth weight infants among these centers are similar,<sup>43</sup> we have previously reported variations in the frequency and extent of physician counseling about outcomes (survival, morbidity, and pain).<sup>19,29,30,32</sup> The results from this study show that the adequacy of parent counseling differs by center and topic. Discussions of morbidity and mortality adequately addressed the information needs of the majority of parents in only 5 of 9 centers. This variability could reflect differing expectations of physicians by parents according to local customs, societal expectations, and cultural norms for or against counseling in these countries. For example, at some centers in which we were not permitted to interview parents of deceased infants because talk of death is a taboo,<sup>48</sup> discussions of the risks of death may be less extensive. Fewer parents in each of the Australasian centers reported counseling on morbid outcomes as adequate than did parents in San Francisco. An East-versus-West cultural explanation of these differences, documented by Veatch,<sup>49</sup> is not probable given that parents in Melbourne were the group least likely, and parents in San Francisco the most likely, to report disability as adequately discussed. Alternatively, this difference could relate a heightened awareness of potential medicolegal liability among California physicians.

In all centers, parents less often reported religion as adequately discussed than they did financial considerations. Some physicians may hesitate to discuss religion but feel that they must know how the infant's medical bills will be paid. Physicians may regard religion as a more private matter that is less germane to antenatal counseling. Counseling on these issues may be curtailed when physicians do not consider them important to resuscitation decisions, as we have shown in California and South Africa.<sup>19,30</sup> In contrast, 47% of Australian neonatologists often or always considered moral or religious considerations in resuscitation decisions for 23- to 25-week-old infants.<sup>29</sup>

Variations in counseling among centers would be expected to the extent that local culture shapes phy-

sicians' attitudes; for example, differing degrees of medical paternalism in these cultures could explain some of the variations in counseling. In Japan, a more paternalistic model of medical care is accepted by physicians and patients.<sup>22</sup> In our study, parents in Tokyo were the least likely to report adequate discussion of mortality. On the other hand, a minority of parents in Melbourne, where the culture is less paternalistic, assessed discussions of mortality as adequate. Parents may recall discussions as adequate while being unaware that they may not have been offered the full range of treatment options. Where there has been less experience with neonatal intensive care (ie, Malaysia), counseling might be less frequent, because physicians feel that they alone have the knowledge and experience required for intensive care decision-making. We have shown previously that counseling is less frequent where limited resources restrict intensive care options in the developing world.<sup>19</sup> A larger proportion of parents in Kuala Lumpur, where neonatal care has been widely available only recently, recalled discussion of the likelihood of a fatal outcome.

Although usually perceived as adequate, counseling seems not to have brought parents' anxieties about NICU death or survival with significant disability into line with local NICU outcome statistics. In-hospital mortality for VLBW infants ranges from 14% to 41% in these centers,<sup>4,5,9,43</sup> but 57% to 78% of parents (in Hong Kong and Singapore, respectively) feared that their infant would die in the NICU. A significant proportion of parents (38–64% in Hong Kong and Singapore, respectively) expected their surviving infant to have sequelae of prematurity, whereas Kuala Lumpur was an outlier at 15%. In fact, the likelihood of surviving with significant disability ranges from 7% to 33% among VLBW infants in these countries.<sup>5,7</sup> Similar discrepancies between physicians' and parents' expectations of outcomes of prematurity have been reported in a high-risk obstetric service in Ontario,<sup>37</sup> in which there was a 76% concordance between parents and physicians on survival probability but only 44% on likelihood of normal development. Physicians may prepare parents for the worst-case scenario, which often heightens their anxiety about reasonably infrequent morbidities.

### Factors Considered in Life-Support Decisions

Our data document remarkable similarities in the bases on which parents make life-and-death decisions across these Australasian cultures, in particular the dominance of physicians' and partners' opinions. The differences between these centers may reflect the cultural milieu in which physicians practice. Compared with other Australasian centers and San Francisco, decisions by parents in Tokyo are less commonly influenced by their partner's opinion, attachment, the likelihood of death, or pain and suffering. In Tokyo and also Taiwan, the likelihood of disability seems to be a less influential factor in decision-making and could reflect a societal tendency to accept physicians' recommendations to try to save lives. Parents have been shown to prefer more ag-

gressive interventions than physicians and nurses.<sup>47</sup> In more paternalistic cultures, parents' hope for their child's survival and acquiescence to physician authority would work synergistically to diminish the importance of other medical concerns or possible medical considerations in their decision-making.<sup>50</sup>

Local availability of health care resources also shapes the treatment options that physicians offer parents<sup>19,42</sup>; however, none of these centers lack resources to an extent that would have forced physicians to restrict treatment options. Our data show that costs of care are differently considered in parents' life-support decisions in these centers, likely reflecting differences in coverage of health care costs. Financial considerations rarely played into parents' decisions in Melbourne, whereas they frequently influenced decisions in Kuala Lumpur and Singapore. A prior study of parents of extremely low birth weight infants in Canada (where health care costs are covered) showed that the costs of care for an impaired child did not greatly affect parents' decisions on life support.<sup>45</sup>

### Decision-Making Roles

In all centers, a significant proportion of parents perceived that the physician had nevertheless played a dominant role in decision-making. In Tokyo, just under half of the parents (45%) felt that physicians had made the decisions for their infant, whereas in Melbourne, a large majority (74%) felt that the physicians had made the medical decisions. The majority of parents in most centers felt that they had made actual life-support decisions collaboratively with physicians. Sole parental discretion in actual decisions was exceptional in all centers.

In contrast, parents' perspectives on optimal decision-making suggest that parents prefer a more collaborative approach. Only in Tokyo did a larger proportion of parents prefer physician decision-making to parental decision-making. Given the salience of autonomy in Western ethics discourses, parents in San Francisco and Melbourne were unexpectedly less likely than Asian parents to conclude that optimally parents should make decisions. In all centers, parents more frequently believed that they should listen to physicians than that physicians should listen to them, a finding at odds with the concept of "primacy of parental decision-making."

As documented in prior studies of life-support decision-making,<sup>33,35,42,50</sup> religious beliefs likely explain some of the variations that we observed. It is not culturally or socially acceptable in Muslim cultures to be explicitly involved or take full responsibility for life-and-death decisions,<sup>50</sup> which would affect results in Singapore and Kuala Lumpur. Religious beliefs were also postulated to explain resuscitation patterns in Europe (where physician attitudes were most strongly associated with country), which the investigators hypothesized reflected the prevailing religion in each country.<sup>35</sup>

Cuttini and co-workers<sup>31</sup> demonstrated marked national variations in parental input into life-support decisions in European NICUs (from 78% in the United Kingdom to none in France). The extent to

which parents should determine life-support decisions remains controversial, increasingly stressed by some physicians and distrusted by others,<sup>45,51,52</sup> validated by ethicists,<sup>41,52,53</sup> and urged by parents.<sup>40,54</sup> Our data show that parents prefer to play a more extensive role in life-support decisions regardless of surrounding culture.

Our data suggest that parents in these Australasian countries prefer a decision-making partnership with physicians who can provide them with necessary medical information on their infant's likely prognosis and the quality of life among survivors. Our findings in Australasian centers are similar to those reported by Zupancic et al<sup>37</sup> in Canada, where 27% of parents preferred that doctors advise them on what to do for an impending preterm delivery in preference to deciding on their own. Our data suggest that parents prefer to be involved in decision-making but not always to be the final arbiters of specific life-support decisions. It is likely that parents in different cultures prefer differing roles. The optimal counseling process must also sound parents out on how active a role they prefer to take in their infant's treatment decisions.<sup>37</sup> Other studies on parents' preferences on life-and-death decisions for premature infants have produced conflicting results, some showing that parents want a primary role in medical decisions and are willing to bear potential adverse consequences<sup>45,55</sup> and others showing that parents seem hesitant to accept primary decision-making capacity.<sup>37,42,56</sup>

### Limitations

Our data may not reflect parents' experiences throughout each of these countries. In comparison to the more sophisticated methods used in the EURONIC survey of physicians and the population-based EPICure study of physician practices,<sup>3,31,33-35</sup> convenience sampling prevents us from generalizing our findings to practices throughout each country.

Our findings are also affected by case mix and response bias. Cultural taboos about death and dying in several centers restricted our access to parents of infants who died in the NICU. The overall survival (96% among our cohort, high in comparison with national outcome statistics in these countries) likely selected for more satisfied parents.<sup>4-7,9</sup> We did not gather admission and outcome data on other infants admitted during the same time period; thus, we cannot determine how representative our sample is of the target population. We also recognize that illness severity affects mothers' recall of stress associated with neonatal intensive care,<sup>57</sup> and our study results may have been differentially affected by neonatal medical acuity or current vital status.

There were small but significant differences in birth weight and gestational age among these centers. There were no differences in length of stay (when data were available). Although this reflects medical acuity to some extent, we unfortunately have no medical assessment of patient acuity. Because we did not control for the interval between NICU discharge and death, we cannot estimate the extent to which time affected parents' opinions of

physician counseling or infant outcome. However, we found no differences in parents' perceived outcome or their satisfaction with outcome between those interviewed within the first year and those interviewed after 1 year. Our data reflect parental perceptions on outcomes rather than rigorous neurodevelopmental assessment at a specified age when cerebral palsy or neurocognitive deficits can be reliably detected. Parents of young infants with unestablished neurodevelopmental outcomes might later rate perinatal counseling as inadequately preparing them for their infant's status once disabilities have been documented. In addition, parents with children well enough to attend follow-up clinics may recall their NICU experiences more positively than parents of those who are sicker or deceased. We would expect this to increase parental anxiety, decrease satisfaction with NICU experience, and augment parents' desire for input into critical decisions, thus amplifying our conclusions.

We could not objectively evaluate differences in what physicians said from what parents heard. Inadequacies in perinatal communication have been documented previously,<sup>37</sup> resulting partly from limited time for counseling and the complexity of medical issues, treatment options, and outcome data.<sup>58,59</sup> Nevertheless, counseling seems to have satisfied parents' needs, as we have documented previously.<sup>42</sup> Given that the focus of counseling is to provide parents information that is necessary for participating in health care decisions for their infant, their subjective assessment is in fact a satisfactory measure of adequacy of information transfer. We admit that some parents may have overreported satisfaction with centers in which critical comments would be culturally inappropriate. We also recognize that translated interviews often fail to adequately detail the interplay of cultural norms and social interactions that shape counseling, physician-family interactions, and parental roles in decision-making.

### CONCLUSIONS

Our data suggest specific topics that physicians may need to address more effectively in counseling parents who are expecting premature infants. Some differences between what physicians say and what parents hear or understand are inevitable; a future prospective study of physician-parent interactions in the perinatal context may clarify ways in which physicians can improve parents' understanding of their infants' diagnosis, any uncertainties in prognosis, and the therapeutic options they may be forced to consider. We hypothesize that a more consistent and comprehensive message about possible decision-making roles will improve parents' experiences and perhaps medical care everywhere. Future studies could also determine if the process can be improved by ensuring time for physicians and parents to interact or by increased use of written or Internet resources.

Our data suggest that parents prefer shared decision-making and that health care professionals should promote parental involvement in life-support decisions. Additional investigation into the extent to which cultural norms and societal standards con-

strain parental decision-making should point to ways in which health care professionals can be culturally sensitive while promoting parental involvement in life-support decisions. This would not require them to be the final decision-maker in all settings; in some cultures, it would foster informed decisions by parents after consultation with physicians. Establishing what parents wish for premature infants born at the limits of local technological capability in different cultural contexts is an important first step toward shared decision-making about resuscitation and life support. Our data support the need to improve providers' cultural sensitivity in counseling high-risk patients. Parents' suggestions for improvement imply a need for national or center-based guidelines for consistent and comprehensive communication with parents. Improved perinatal counseling should decrease parents' anxiety, provide them support in difficult circumstances, and improve their satisfaction with nursery counseling.

#### APPENDIX: INTERVIEW QUESTIONS (TOPICS)

Is the infant deceased, living at home, or living in another facility/hospital?

Does the child have any medical problems or disabilities? (In regard to eating, walking, talking, hearing, vision, breathing, taking daily medications, or needing special medical care?)

After you brought your child home, did you expect him/her to have any problems/disabilities? (If yes, was it better or worse than expected?)

Did you think your infant might die (when in the nursery, after the infant was home)?

Did you understand clearly how your infant would be after you took him/her home?

How helpful were the doctors in talking to you about medical therapies that would occur after your infant's birth?

Who at the hospital was most helpful in talking to you about your infant's treatment and condition in the nursery?

Did your doctor discuss with you the option of withholding resuscitation at delivery?

Did your doctor estimate your infant's likelihood of survival after resuscitation?

Which of the following factors concerned you when making decisions about intensive care options for your infant? (emotional attachment to infant, spouse/partner opinion, opinions of family members, doctor's advice, possibility of death, possibility of severe disability/medical problems, experience of pain, financial considerations, religious/moral considerations, experience with sick infants or family members, knowledge of problems premature infant can have, information from pamphlets)

In speaking with the doctors regarding intensive care options, were the following factors adequately discussed? (emotional attachment, spouse/partner opinion, opinions of family members, possibility of death, possibility of severe disability/medical problems, experience of pain, financial considerations, religious/moral considerations)

Who made the life-support decisions for your infant? (the doctor alone, the doctor after consulting with me

and my partner, the doctor and I made the decision together, we made the decision after consulting with the doctor, we alone made the decision)

Tell me how much you agree with the following statements about initial care and life support in the delivery room? (The family should make all the decisions, the family should listen to what the doctors say, the family and doctors should make decisions together, the doctors should make decisions based on family's wishes, the doctors should make all the decisions)

What was most important to you in deciding what kind of initial treatment your infant should have? (information from doctors, your religious views, needs of family members, costs of treatment, availability of health insurance/financial aid, experience with sick newborns or family members, knowledge about problems premature infant can have, information from pamphlet)

How satisfied are you with communication about the care that your infant received?

How satisfied are you with the amount and level of care that you and your family received while your infant was in the NICU?

Which of the following would you suggest as important changes for NICU care? (more frequent meetings with doctors, more involvement by nurses, more involvement by social workers, have someone who speaks my language, have discussions in simpler words, be more specific about possible outcomes, have discussions with someone of my ethnic/cultural background, provide more written materials, more response to my emotional needs)

Parents' and infant's demographics: (age at delivery, ethnicity, religious beliefs, years of education; infant's birth weight, infant's gestational age, delivery method, date of birth, singleton vs multiple gestation, NICU diagnoses).

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