



Attitudes of Parents and Health Care Workers to Major Surgery for High-Risk Preterm Infants

Hugh Simon Lam, MRCPCH¹, Tony Sit, PhD², Chi Lok Chau, MA¹, Yuk Him Tam, FRCS(Edin)³, Hon Ming Cheung, MRCPCH¹, Samuel Po Shing Wong, PhD², and Pak Cheung Ng, FRCPC¹

Objectives To assess preferences of health care workers (HCWs) and parents of term and preterm infants to adverse health outcomes, and how perceived surgical mortality influences decision-making.

Study design A total of 536 participants (157 HCWs, 201 parents of term infants, and 178 parents of preterm infants) were recruited to take part in a structured interview. Preferences related to treatment of a critically ill preterm infant with necrotizing enterocolitis were measured by health state rank permutation analysis and pivotal risk analysis. Between-group and subgroup comparisons were performed.

Results HCWs rank adverse health states less favorably than parents of preterm infants, consistently ranking 2 of the most adverse health states worse than death. Pivotal risk values of HCWs for all health states were consistently the lowest of the 3 groups. High operative mortality was associated uniformly with reduction in pivotal risks for all groups both in favorable and adverse health states. Subgroup analyses revealed significant discrepancies in preferences between fathers and mothers as well as doctors and nurses. Regular religious practice was significantly associated with increased pivotal risks in parental subgroups.

Conclusions As discrepancies in health state preferences existed between subgroups (ie, doctors vs nurses, mothers vs fathers) and perceived operative mortality consistently biased parental and HCW health state preferences, we recommend that HCWs should first identify differences regarding patient management before interviewing the parents together. HCWs should be aware of inadvertently biasing parents when discussing the risks and outcomes of surgery in conjunction with the overall long-term prognosis of the underlying condition. (*J Pediatr* 2016;177:78-83).

With continuing improvements in neonatal surgery and perioperative intensive care, the survival of critically ill preterm infants has become increasingly common.¹⁻⁴ Many infants with major surgical conditions subsequently develop severe long-term complications that extend beyond the initial surgical complications, such as chronic lung injury secondary to prolonged mechanical ventilation and immune-mediated injury to the central nervous system.⁵ Decisions on whether to pursue surgery in preterm infants at high risk of developing major neurologic and surgical morbidities depend not only on legal and moral views of society but also parental and health care worker (HCW) preferences, religious beliefs, cultural background, and socioeconomic factors.⁶⁻¹¹

To our knowledge, published studies have only explored preferences of parents and HCWs towards existing complications of prematurity and whether or not to discontinue life support.^{6,7,9-12} Although surgical scenarios are encountered commonly, it has not been investigated how preferences change when definitive treatment is surgical and associated with high treatment-related mortality and morbidity. Improved understanding of preferences and attitudes of parents and HCWs could help to improve the fidelity of simulation-based communication skills training and the ability of specialists to assist stressed parents in making appropriate decisions.

The objective of this study was to use rank permutation and pivotal risk analyses to assess the difference in preference to various adverse health states among HCWs, parents of term infants, and parents of preterm infants (defined as infants <32 weeks' gestation and birth weight <1500 g), and how operative mortality influences their decision-making. In addition, we aimed to compare the preferences among subgroups (ie, doctors vs nurses, and fathers vs mothers).

Methods

All participants were recruited from a university-affiliated teaching hospital. Our neonatal intensive care unit is 1 of 3 tertiary referral centers for neonatal surgical cases in Hong Kong. Three groups of participants were recruited: HCWs (pediatric doctors and nurses), parents of term infants, and parents of preterm infants. Parents of term infants were assumed to be representative of parents of newborn

From the ¹Department of Pediatrics, Prince of Wales Hospital, The Chinese University of Hong Kong, Hong Kong, China; ²Department of Statistics, The Chinese University of Hong Kong, Hong Kong, China; and ³Division of Pediatric Surgery, Department of Surgery, The Chinese University of Hong Kong, Hong Kong, China

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HCW	Health care worker
NEC	Necrotizing enterocolitis

infants. Thus, the comparisons between parents of term infants and parents of preterm infants were believed to provide insight into how parents' preferences could change as they gained experience of providing long-term care to a preterm and/or disabled infant, while at the same time removing the need to control for the emotional impact of recent childbirth. Participants were excluded if they: (1) did not understand the purpose of the interview (eg, due to language barriers); (2) did not understand the concepts of probability, proportion, and percentage; (3) had a history of major psychiatric illness; or (4) at the time of interview had a child who had undergone major surgery or received intensive care treatment within the previous 3 months, to avoid triggering any traumatic memories regarding their child and any emotional impact on decision-making during the structured interview. For the parents of term infants group, parents who had a previous child born prematurely or had been admitted to the neonatal intensive care unit were excluded. Written informed consent was obtained from all study participants, and the study was approved by the Joint Chinese University of Hong Kong - New Territories East Cluster Clinical Research Ethics Committee.

Participants were interviewed by a trained research assistant via a standardized technique described in our previous report.⁹ The demographic data collected included information on participant sex, age, marital status, number of children, education level, occupation, religious belief and frequency of worship, and for HCWs, duration of professional experience. Each interview comprised 3 sections (**Figure 1**; available at www.jpeds.com). Each interview took approximately 50 minutes.

Participants were asked simple questions to familiarize them with the notion of probability, proportion, and percentage. Participants who did not understand these concepts were excluded from the study. Participants were presented with 5 cards, each describing a different health state (1-5) with varying degrees of physical, neurologic, respiratory, and social disabilities (**Table I**). Although not revealed to the participants, each health state was designed to emphasize a particular aspect of development. Participants were first asked to rank health states 1-5 in ascending order of severity and then to place a sixth card, labeled "death" in the established ranking.

Each participant was then asked to imagine that he or she was the parent of a critically ill infant born at 26 weeks' gestation with necrotizing enterocolitis (NEC) who was not improving despite medical therapy. NEC was chosen because it represents the most commonly encountered surgical emergency affecting preterm infants and is associated with high mortality and long-term morbidity. Two options were presented: conservative management with 100% chance of dying and laparotomy with bowel resection, which would lead to gastrointestinal complications and the possibility of various long-term disabilities (health states 1-5) (**Table I**). Using a visual analogue probability scale expressed in percentages, we asked each participant if he/she would choose to proceed with laparotomy at varying levels of probability that a given health state would develop. Pivotal risk^{7,9} was defined as the maximum probability that the participant accepted for each of the 5 health

states before switching from accepting to refusing surgery. Pivotal risks represent the degree of acceptance by an individual of a health state. The lower the pivotal risk, the less favorable the health state is perceived to be. We previously used the same tool as a measure of preference to health states that may result from intensive care treatment of a critically ill premature infant,⁹ and it is similar to the concept of utility used by other investigators.^{7,11} The determination of pivotal risk for each of the 5 health states was performed, once assuming low operative mortality (20%) and then again assuming high operative mortality (80%).

Rank permutation patterns of the 3 groups were compared with the Pearson χ^2 test with correlation adjustment for paired couples within the parent groups (ie, parents of preterm infants and parents of term infants). Pearson goodness-of-fit test was repeated to test for intersubgroup homogeneity, to evaluate whether there was significant discrepancy between subgroup pairs, ie, doctors vs nurses, fathers vs mothers. Linear mixed effects models were adopted to predict pivotal risk levels of subjects and to handle the correlation between paired couples in the parent groups. Covariates entered into stepwise regression models were participant sex, child factors (gestational age and number of complications), education level (parents only), religious practice, marital status, number of children, years of professional experience (HCWs only), and profession (nurse or doctor) and were retained in the model if $P < .10$. All tests were 2-tailed and performed by our statisticians (T.S., S.W.) using R (The R Foundation for Statistical Computing, Vienna, Austria).

Results

Of 578 subjects approached, 16 parents of preterm infants, 11 parents of term infants, and 6 HCWs did not wish to participate. In addition, 2 parents of preterm infants and 7 parents of term infants did not understand the concept of probability and were excluded. Thus, a total of 536 participants completed the entire interview (**Table II**; available at www.jpeds.com).

Despite 720 possible rank permutations (ie, $6 \times 5 \times 4 \times 3 \times 2 \times 1$), participant choices clustered around a limited number of patterns. Each of the 6 states (5 health states and death) was arbitrarily classified as "adverse" or "favorable." The 3 states ranked most severe were defined as adverse, and the remaining 3 were defined as favorable. A total of 79.5% of subjects ranked health state 3, health state 5, and death as adverse and 81.9% of subjects ranked health state 1, health state 2, and health state 4 as favorable. Overall, "5-death-3" and "death-5-3" were the 2 most frequent rank permutations for the adverse states (38.8% and 26.5%, respectively), whereas "2-1-4" and "1-2-4" were the 2 most common permutations for the favorable states (42.4% and 34.7%, respectively).

Doctors showed less variation in ranking preferences than all the other subgroups, with 29.3% choosing 5-death-3-2-1-4, the most common permutation, compared with 13.5% to 21.9% in the other 5 subgroups (**Figure 2**; available at www.jpeds.com). Overall, parents of preterm infants and HCWs

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