Differences in Preferences for Neonatal Outcomes Among Health Care Professionals, Parents, and Adolescents

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WITH RECENT IMPROVEMENTS in survival of infants of borderline viability, the issue of whether to treat such infants actively continues to be debated.1-9 Both the Canadian Paediatric Society10 and the American Academy of Pediatrics11 have issued statements encouraging the involvement of parents in decision making, and in fact, to support the primacy of parental decisions for all infants at the threshold of viability. These statements were developed by health professionals using data on the mortality and morbidity of infants at each gestational age, without explicit consideration of the values and preferences of parents or members of society.

In critical care situations involving newborns, parents often assume responsibility for making important life-sustaining decisions, along with neonatologists. Obviously, the preferences of newborns are unknown, and it is assumed that parents will take the best interests of the infant and the family into account. However, there may be a difference in the preferences of the parents and health care professionals.

Context In neonatal intensive care, parents make important clinical management decisions in conjunction with health care professionals. Yet little information is available on whether preferences of health care professionals and parents for the resulting health outcomes differ.

Objective To measure and compare preferences for selected health states from the perspectives of health care professionals (ie, neonatologists and neonatal nurses), parents of extremely low-birth-weight (ELBW) or normal birth-weight infants, and adolescents who were either ELBW or normal birth-weight infants.

Design Cross-sectional cohort study.

Setting and Participants A total of 742 participants were recruited and interviewed between 1993 and 1995, including 100 neonatologists from hospitals throughout Canada; 103 neonatal nurses from 3 regional neonatal intensive care units; 264 adolescents (aged 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.

Results Overall, neonatologists and nurses had similar preferences for the 5 health states, and a similar proportion rated some health states as worse than death (59% of neonatologists and 68% of nurses; \( P = .20 \)). Health care professionals rated the health states lower than did parents of ELBW and term infants (\( P < .001 \)). Overall, 64% of health care professionals and 45% of parents rated 1 or more health states to be worse than death (\( P < .001 \)). Differences in mean utility scores between health care professionals and parents and adolescent respondents were most pronounced for the 2 most severely disabled health states (\( P < .001 \)).

Conclusions When asked to rate the health-related quality of life for the hypothetical conditions of children, health care professionals tend to provide lower utility scores than do adolescents and their parents. These findings have implications for decision making in the neonatal intensive care unit.


For editorial comment see p 2041.
into consideration. But it is not clear whether parents are influenced by health care professionals, and if they are, to what extent those decisions are based on the preferences of the very individuals on whom they rely for information and advice: neonatologists, neonatal nurses, and their personal physicians. Thus, it is important to determine whether the preferences of medical personnel are similar to or differ systematically from patients who were extremely low-birth-weight (ELBW) infants or their parents and to measure the direction of these differences, if any.

The principle underlying the measurement of preferences is to allow individuals to provide their preferences for alternative health outcomes. Values and utilities are the 2 types of cardinal preferences. Values are preferences measured under conditions of certainty. Conversely, utilities are preferences measured under conditions of uncertainty. Torrance et al suggest that utility is the appropriate construct for use in health problems involving uncertainty and should be used as the primary measure of health-related quality of life (HRQL).

This study seeks to measure and to compare preferences (mean utility scores) for certain hypothetical health states from the perspective of neonatologists and neonatal nurses (health care professionals [HPs]) and to compare the utilities of HPs with those obtained from parents of ELBW and term infants and from adolescents who were ELBW or term infants. A secondary objective is to explore correlates of the above utilities, ie, are there any physician or parent characteristics that correlate with their preferences for selected health states? We hypothesized that utility scores obtained from physicians would be systematically different from those obtained from neonatal nurses and that the utility scores from HPs would differ systematically from those obtained from parents and from the adolescents themselves. A secondary hypothesis was that utility scores provided by physicians, nurses, and parents would not be significantly correlated with demographic variables.

**METHODS**

**Study Participants**

A large national sample of physicians working in level 3 (tertiary care) neonatal referral centers throughout Canada were recruited for face-to-face interviews from the Canadian Paediatric Society Meeting, Montreal, Quebec, June 1995 (n = 53), 2 neonatal centers in Winnipeg, Manitoba (n = 7), and in 5 neonatal centers in Ontario (n = 27). This sample provided 87 neonatologists or 64% of the neonatologists working in Canadian tertiary care centers, with representation from all provinces except Newfoundland and Saskatchewan. An additional 13 physicians were recruited from level 2 plus units (with capabilities of providing short-term neonatal intensive care) in Ontario, for a total of 100 physicians. There were no refusals.

A total of 103 neonatal nurses were recruited from 3 tertiary care centers, with 69 of them working in either an inborn or outborn center in Toronto and 34 working in a combined inborn and outborn center in Hamilton, Ontario, representing the 3 types of neonatal intensive care units in Canada. A list of all nurses was obtained from the respective units and numbers were assigned from a random number table. The refusal rate was 18%. The most frequent reason for declining participation was busy patient assignments during the interview schedule. The HPs were interviewed between March and September 1995.

Adolescents who were ELBW infants, born between 1977 and 1982 in a geographically defined region in central-west Ontario, were followed up longitudinally from birth. They were matched for sociodemographic factors with a control group of children who were born at term and weighed more than 2500 g at birth. The control children were recruited when they were 8 years old. Of the 314 adolescents who were asked to participate in the survey, 264 (84%) were interviewed, 140 (83%) of 169 adolescents who had been ELBW infants were interviewed, and 124 (86%) of 145 subjects in the control group were interviewed. Both cohorts were between the ages of 12 and 16 years. Preferences from these 2 groups have been previously compared.

Of the parents of adolescents who had been ELBW infants, 149 (88%) of 169 agreed to be interviewed, and 126 (87%) of the 145 parents of children in the control group agreed to be interviewed. Parental preferences have been published in abstract form. The interviews of the children and their parents took place on the same day during 1993 and 1994.

**Measurement of HRQL (Utilities)**

We followed the protocol used in our previous study as closely as possible. Respondents were asked to provide utility scores for 5 hypothetical health states (described below) using the standard gamble, assisted by a chance board. Given that standard gamble responses include the risk preferences of respondents and that risk is intrinsic to clinical decision making for infants who require neonatal intensive care, the standard gamble is an appropriate technique for preference measurement in this context. The reliability of the utility measures was not assessed within the study. Published evidence indicates acceptable levels of reliability but a lack of precision at the level of individual scores. The instrument was extensively pilot tested on nonstudy subjects.

**Hypothetical Health States**

Five hypothetical health states were preselected from those reported by ELBW survivors when they were 8 years old as methodologic reference states for assessment by HPs. Four of these health states were common to a previous study. A fifth health state was selected from the same source for HPs, while parents were asked to consider the fifth health state as if it were their child’s health state. The health-state descriptions were written in the format of...
the Mark 2 version of the Health Utilities Index. Each hypothetical health state was given a unisex name (Jamie, Chris, Pat, Sandy, and Alex) (Table 1). The HPs and parents were asked to imagine themselves living in each of the above states of health for the next 60 years. This time frame was considered the duration of the projected life expectancy of the adolescents in our previous study.

**Interview Protocol**

Each parent and HP was interviewed in a private room by a trained, professional, nonmedical interviewer. Parents and HPs were asked to provide preference measurements for the hypothetical health states using the chance board. At the end of the study, the interviewers evaluated the respondent's comprehension and concentration on the tasks assigned, using a 5-point Likert scale. The respondents also were asked whether they encountered any difficulties and whether the measurement tasks allowed them to represent their opinions. These data were subsequently analyzed to assess the quality of interviews. The entire interview took an hour.

**Demographic Information**

Demographic information was obtained from the HP and parent respondents by a self-administered questionnaire that collected information about each respondent's age, sex, marital status, number of children, education, professional experience, and participation in religious services. Information on prior experience with children with disabilities (personal and/or professional) was obtained from HPs only. These data were used in the analyses to test whether there were any correlations between these variables and the preference scores for health states.

**Consent and Ethics Approval**

Written informed consent was obtained from all respondents who agreed to participate in the study. The study was approved by the ethics review board of the Hamilton Health Sciences Corporation, Hamilton, Ontario.

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**Data Analyses**

**Sample Size and Statistical Testing Power.** Based on variability of previously measured utility scores, a conventional difference of 0.10 utility units (10% of full-scale) was considered to represent a clinically important difference between groups for use in power analyses. A sample of 100 physicians and 100 nurses provides greater than 80% power on 2-tailed tests of significance to detect a difference of at least 0.10 utility units between groups.

**Standardization of Preference Scales.** Preference scores were standardized across raters to a scale, in which perfect health equals 1.0 and being dead equals 0, to ensure comparability when aggregating results across individuals. Briefly, in cases in which the rater considered the health state to be worse than death, the negative utility for the state was determined directly from the standard gamble. The negative utilities were then rescaled to a −1.0 to 0.0 interval using the nonlinear transformation, $y = x/(1 − x)$, first described by Patrick et al. Positive scores were not transformed. The utility scores have interval-scale properties.

**Statistical Tests**

We used the $t$ test to analyze equality of mean utility scores between nurses and pediatricians and between HPs and parents. This test was also used for comparison of mean scores among demographic groups. The variance ratio test was used to test homogeneity of variance between mean utility scores, and 2-way analysis of variance was used to test for relationships between utility scores and demographic variables. Pearson $\chi^2$ with Yates correction for continuity was used to test for differences in proportions of nurses and pediatricians who considered states to be worse than death.

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**RESULTS**

**Demographic Characteristics of Respondents**

The demographic information on HPs and parents is shown in Table 2. The nurses were younger than the neonatologists, all were female, and a smaller proportion were married or had children. A significantly lower proportion of the physicians were born in Canada, the duration from graduation was longer than for nurses, and the majority were working full-time. Although a higher proportion of pediatricians than nurses reported professional experience with disabled patients, there were no differences in the proportion with personal experience with such per-

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**Table 1. Descriptions of Hypothetical Health States**

<table>
<thead>
<tr>
<th>Health State</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jamie</td>
<td>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.</td>
</tr>
<tr>
<td>Chris</td>
<td>Can see, hear, and talk normally. Needs the help of another person, as well as equipment, to walk. Sometimes angry, worried, or sad. Can learn and do schoolwork normally without special help. Can eat, bathe, dress, and use the toilet normally. Free of pain.</td>
</tr>
<tr>
<td>Sandy</td>
<td>Has a problem seeing, hearing, or talking even with glasses or hearing aid. Needs to use equipment, but not the help of another person, to walk. Sometimes angry, worried, or sad. Learns schoolwork very slowly and needs special help. Needs to use special equipment to eat, bathe, dress, or use the toilet. Sometimes has pain, maybe needs Tylenol, but the pain does not prevent normal activities.</td>
</tr>
<tr>
<td>Pat</td>
<td>Blind, deaf, or unable to talk. Needs to use equipment, but not the help of another person, 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, maybe needs Tylenol, but the pain does not prevent normal activities.</td>
</tr>
<tr>
<td>Alex</td>
<td>Able to see, hear, and speak normally for age. Able to walk, bend, lift, jump, and run normally for age. Occasionally fretful, angry, irritable, anxious, depressed, or experiencing &quot;night terrors&quot;. Learns and remembers schoolwork normally for age. Eats, bathes, dresses, and uses toilet normally for age. Free of pain and discomfort.</td>
</tr>
</tbody>
</table>
sons. There were no differences in the proportion who participated in religious activities such as going to a church or synagogue and participating in other religious activities. The academic rank of the physicians was professor, 17%; associate professor, 34%; assistant professor, 39%; and other, 10%. Nursing qualifications were nursing diploma, 75%; bachelor of science degree in nursing, 22%; postgraduate, 1%; and other, 2%.

The demographic variables of parents of ELBW and control infants are presented as combined data to represent consumers. The mean age of parents was 42 years, and 71% were born in Canada. The proportion of married persons was 88%, and the respondents were primarily mothers (89%). Maternal education was as follows: less than high school, 26%; high school diploma, 27%; and postsecondary and college or university, 47%. There were no differences between HPs and parents in the proportion of those who participated in religious activities.

The mean (SD) age of the adolescents at the time of the interview was 14.2 (1.6) years. All children were attending school.

Comparison of Preference Scores for Hypothetical Health States

Physicians and Nurses. Descriptive statistics of mean utility scores on the chance board for the 5 hypothetical scenarios provided by physicians and nurses are presented in Table 3. There were no statistically significant differences in the mean or median scores between physicians and nurses, except for health state for Alex. For this reason, data for physicians and nurses are combined for the rest of the analyses. Mean and median utility scores for Pat and Sandy were equivalent to death or lower. There was considerable variability in the scores provided by both groups. Overall, 59% of physicians and 68% of nurses rated 1 or more hypothetical health states to be worse than death ($P = .20$).

HPs and Parents. Four of the 5 hypothetical health states (Alex excluded) rated by HPs were also rated by parents and adolescents in our previous studies. Because there were no significant differences in the mean utility scores for the hypothetical health states between physician and nurses and between the 2 groups of parents, combined data for parents and HPs are presented in Table 4.

Overall, HPs rated the hypothetical health states lower than parents ($P < .001$). There were no differences between HPs and parents in the mild to moderately disabled hypothetical health states (Jamie and Chris). However, HPs rated the 2 most severely disabled health states significantly lower than parents (mean [SD] utility scores for Pat: HPs, $-0.05 \pm 0.53$; parents, $0.20 \pm 0.51$; $P < .001$; for Sandy: HPs, $0.05 \pm 0.50$; parents $0.23 \pm 0.51$; $P < .001$) (Table 4).

The Table shows the comparison of mean utility scores and 95% confidence intervals (CIs) between parents

### Table 2. Sociodemographic Data: Physicians, Nurses, and Parents*

<table>
<thead>
<tr>
<th>Age, mean (SD), y</th>
<th>Physicians (n = 100)</th>
<th>Nurses (n = 103)</th>
<th>Parents (n = 276)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>46 (10)</td>
<td>37 (8)†</td>
<td>42 (5)</td>
</tr>
<tr>
<td>Male, %</td>
<td>60</td>
<td>57†</td>
<td>56†</td>
</tr>
<tr>
<td>Born in Canada, %</td>
<td>39</td>
<td>74</td>
<td>71§</td>
</tr>
<tr>
<td>Married (or 2 parents), %</td>
<td>79</td>
<td>54†</td>
<td>88†</td>
</tr>
<tr>
<td>Have children, %</td>
<td>82</td>
<td>50†</td>
<td>100</td>
</tr>
<tr>
<td>N. of children, mean (SD)</td>
<td>2 (1)</td>
<td>1 (1)†</td>
<td>2 (1)</td>
</tr>
<tr>
<td>Years since graduation, mean (SD)</td>
<td>21 (10)</td>
<td>13 (8)†</td>
<td>...</td>
</tr>
<tr>
<td>Years in NICU, mean (SD)</td>
<td>14 (9)</td>
<td>10 (5)†</td>
<td>...</td>
</tr>
<tr>
<td>Full-time employee, %</td>
<td>95</td>
<td>76†</td>
<td>72</td>
</tr>
<tr>
<td>Type of NICU, %</td>
<td>Inborn only</td>
<td>17</td>
<td>39</td>
</tr>
<tr>
<td></td>
<td>Outborn only</td>
<td>12</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td>Inborn plus outborn</td>
<td>71</td>
<td>33</td>
</tr>
<tr>
<td>Experience with disabilities, %</td>
<td>Professional</td>
<td>94</td>
<td>77†</td>
</tr>
<tr>
<td></td>
<td>Personal</td>
<td>64</td>
<td>65</td>
</tr>
<tr>
<td>Religious participation, %</td>
<td>Almost every week/more than just on holidays</td>
<td>42</td>
<td>55</td>
</tr>
<tr>
<td></td>
<td>Only on holidays/never or never</td>
<td>58</td>
<td>45</td>
</tr>
</tbody>
</table>

*Ellipses indicate that information is unavailable; NA, not applicable; and NICU, neonatal intensive care unit.

<table>
<thead>
<tr>
<th>Hypothetical Health State</th>
<th>Group</th>
<th>Mean</th>
<th>Median</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Differences</th>
<th>$P$ Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jamie</td>
<td>Physicians</td>
<td>0.82 (0.18)</td>
<td>0.93</td>
<td>0.10</td>
<td>0.95</td>
<td>0.04</td>
<td>.20</td>
</tr>
<tr>
<td></td>
<td>Nurses</td>
<td>0.78 (0.31)</td>
<td>0.85</td>
<td>-0.95</td>
<td>0.95</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chris</td>
<td>Physicians</td>
<td>0.66 (0.32)</td>
<td>0.75</td>
<td>-0.75</td>
<td>0.95</td>
<td>0.08</td>
<td>.10</td>
</tr>
<tr>
<td></td>
<td>Nurses</td>
<td>0.58 (0.39)</td>
<td>0.65</td>
<td>-0.85</td>
<td>0.95</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pat</td>
<td>Physicians</td>
<td>-0.03 (0.49)</td>
<td>0.00</td>
<td>-0.95</td>
<td>0.95</td>
<td>0.04</td>
<td>.60</td>
</tr>
<tr>
<td></td>
<td>Nurses</td>
<td>-0.07 (0.56)</td>
<td>-0.10</td>
<td>-0.95</td>
<td>0.95</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sandy</td>
<td>Physicians</td>
<td>0.05 (0.48)</td>
<td>0.10</td>
<td>-0.95</td>
<td>0.95</td>
<td>0.01</td>
<td>&gt; .99</td>
</tr>
<tr>
<td></td>
<td>Nurses</td>
<td>0.04 (0.52)</td>
<td>0.00</td>
<td>-0.95</td>
<td>0.95</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alex</td>
<td>Physicians</td>
<td>0.86 (0.18)</td>
<td>0.95</td>
<td>0</td>
<td>0.95</td>
<td>0.07</td>
<td>.02</td>
</tr>
<tr>
<td></td>
<td>Nurses</td>
<td>0.79 (0.22)</td>
<td>0.85</td>
<td>-0.55</td>
<td>0.95</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Differences and $P$ values represent differences in mean utility scores between physicians and nurses (physicians minus nurses).
and HPs. As can be seen, the mean utility scores were similar for Jamie and Chris. However, the mean utility score provided by HPs for Pat was below 0 (or worse than death), and the CIs were below 0 for both Pat and Sandy. Overall, 64% of HPs and 45% of parents rated 1 or more health states to be worse than death \( (P<.001) \).

**HPs and Adolescents.** Data from ELBW and Control Adolescents were combined for purposes of comparisons with HPs (Table 4). The mean utility scores of adolescents for the 2 more morbid health states (Pat and Sandy) were significantly higher than the mean utility scores of HPs. However, the mean utility scores of adolescents were significantly lower than those of parents and HPs for health states with milder impairments (Jamie and Chris). Overall, 50% of adolescents rated at least 1 of the health states as worse than death, significantly fewer than the health professionals \( (P=.004) \).

### Association Between Demographic Variables and Utility Scores

We did not find interactions between the demographic factors of HP and individual health states. The following demographic variables were not associated with preference scores: age of respondent, marital status, country of birth (Canada or other), participation in religious services, and personal and professional experience with children with disabilities. Female HPs \( (P=.003) \) and those who were childless \( (P=.04) \) tended to assign lower scores to the health states. The effect of sex on preference scores was also significant among physicians, with women providing lower ratings than men \( (P=.01) \). However, the Pearson correlation between utility scores and statistically significant demographic variables showed that very little of the total variability in utility scores was explained by these factors, \( r \) less than 10%.

The following demographic variables of parents were associated with lower scores: female sex \( (P=.03) \); age older than 40 years \( (P=.007) \); and country of birth other than Canada \( (P<.001) \). Parental educational background, income, marital and employment status, and participation in religious services were not associated with preference scores.

### Comment

Current financial constraints on health care resources make it imperative to define better both health care outcomes achieved and the costs of achieving those outcomes. It is also necessary to obtain information on the relative desirability of outcomes. One way to do this is to measure preferences (or utilities) of health state outcomes. The greater the gain in utility achieved by a program, all other things being equal, the more deserving the program becomes for consideration for implementation.

However, it is unclear whose preferences for health states should be considered in program evaluation and resource allocation decisions. The possibilities are many—people such as consumers (patients themselves, or their parents in the case of children), health care providers (physicians, nurses, and allied HPs), or members of society (community members, taxpayers). If the preferences of these groups are similar, then for programmatic decisions (as opposed to patient management), it may not matter whose preferences are used. If, however, preferences differ systematically, a number of implications follow. First, it is important to document descriptively any differences that exist. Second, the results of program evaluations such as cost-utility analyses may depend on whose preferences are considered. Third, systematic differences in preferences may affect decisions concerning patient care. Thus, the determination of whether significant differences exist is an important step in formulating strategies to align

### Differences in Preferences for Neonatal Outcomes

<table>
<thead>
<tr>
<th>Hypothetical Health State</th>
<th>Group</th>
<th>Mean (SD)</th>
<th>Median</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Differences</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jamie HPs</td>
<td>0.80 (0.25)</td>
<td>0.85</td>
<td>-0.95</td>
<td>0.95</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>0.82 (0.19)</td>
<td>0.90</td>
<td>0.00</td>
<td>1.00</td>
<td>-0.02</td>
<td>.20</td>
<td></td>
</tr>
<tr>
<td>Adolescents</td>
<td>0.72 (0.25)</td>
<td>0.75</td>
<td>0.00</td>
<td>1.00</td>
<td>0.08</td>
<td>.002</td>
<td></td>
</tr>
<tr>
<td>Chris HPs</td>
<td>0.62 (0.36)</td>
<td>0.70</td>
<td>-0.85</td>
<td>0.95</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>0.63 (0.33)</td>
<td>0.75</td>
<td>-0.95</td>
<td>0.95</td>
<td>-0.01</td>
<td>.70</td>
<td></td>
</tr>
<tr>
<td>Adolescents</td>
<td>0.56 (0.31)</td>
<td>0.65</td>
<td>-0.85</td>
<td>0.95</td>
<td>0.06</td>
<td>.04</td>
<td></td>
</tr>
<tr>
<td>Pat HPs</td>
<td>-0.05 (0.53)</td>
<td>0.00</td>
<td>-0.95</td>
<td>0.95</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>0.20 (0.51)</td>
<td>0.30</td>
<td>-0.95</td>
<td>0.95</td>
<td>-0.25</td>
<td>&lt;.001</td>
<td></td>
</tr>
<tr>
<td>Adolescents</td>
<td>0.16 (0.50)</td>
<td>0.15</td>
<td>-0.95</td>
<td>0.95</td>
<td>-0.21</td>
<td>&lt;.001</td>
<td></td>
</tr>
<tr>
<td>Sandy HPs</td>
<td>0.05 (0.50)</td>
<td>0.00</td>
<td>-0.95</td>
<td>0.95</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>0.23 (0.51)</td>
<td>0.25</td>
<td>-0.95</td>
<td>0.95</td>
<td>-0.18</td>
<td>&lt;.001</td>
<td></td>
</tr>
<tr>
<td>Adolescents</td>
<td>0.23 (0.47)</td>
<td>0.25</td>
<td>-0.95</td>
<td>0.95</td>
<td>-0.18</td>
<td>&lt;.001</td>
<td></td>
</tr>
</tbody>
</table>

*Differences and \( P \) values represent differences in mean utility scores between health care professionals (HPs) and parents (HPs minus parents) and HPs and adolescents (HPs minus adolescents). Negative differences indicate HPs provided lower scores.*

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

Mean utility scores and 95% confidence intervals. HP indicates health care professionals (neonatologists and neonatal nurses); P indicates parents of adolescents who were extremely low-birth-weight or term infants.
better the practice of neonatal intensive care with the preferences of interested parties. Such comparisons have not been made before in the pediatric population. Our research is directed toward these issues.

First, we measured preferences for hypothetical health states from the perspective of physicians and neonatal nurses. Our concern was that if the preferences of physicians and nurses differed, this may contribute to some conflict in the formulation and execution of treatment policies. Contrary to the literature and the prevailing perception, no statistically significant differences were observed between the HRQL ratings provided by physicians and nurses. On the whole, HRQL ratings of HPs were consistent with the severity of the health states. Both physicians and nurses reported the 2 most disabled health states as having mean scores near 0 or below. This consistency in valuation of HRQL by health care providers working as a team in the neonatal intensive care unit is reassuring.

Comparison of preferences for the same health states obtained from HPs and parents revealed that although the overall HRQL scores provided by HPs were lower, differences in mean scores were most pronounced for the 2 most morbid health states (Pat and Sandy). It appears that HPs and parents view the mild to moderately disabled health states similarly, but parents were more accepting of the severely disabled health states than HPs. Our findings support the observation that HPs tend to provide lower HRQL scores for patients than other respondents. We have shown previously that as a group, adolescents who were ELBW or term infants rated the same health states lower than their parents. However, there appears to be more consistency between adolescents and their parents for the severely disabled health states than between adolescents and HPs. This finding lends support to the concept that parents are the most appropriate agents when making decisions on behalf of their infants in the neonatal intensive care unit.

The literature on preferences of health care providers and consumers in the pediatric population is sparse. Our findings of differences in valuation between HPs and patients are in accord with studies on adult subjects. Churchill et al compared mean visual analog scale value scores for health states of adult patients with end-stage renal disease as reported by patients, physicians, and nurses. The trend appeared for patients to value their own health conditions more highly than did nurses and physicians. In another study, patients with cancer were reported to be more willing to opt for radical treatment with minimal chance of benefit than subjects without cancer, including HPs. Currently, we have limited knowledge of the processes by which individuals arrive at these judgments, but it appears that the perceived value of life changes appreciably when a person has to cope with a disability or when faced with a life-threatening situation.

This is the first time, to our knowledge, that comparisons of preferences (utilities) have been made between HPs, health care consumers, and members of the community in a pediatric context. We have shown that adolescents, parents of ELBW infants, and parents from the community provide higher ratings for the HRQL of severely disabled children than do HPs. Although a significant proportion of HPs are also parents themselves, the discrepancy in valuation between them and other respondents may reflect their clinical bias. It is possible that this might affect the choice of management options offered to parents in the neonatal intensive care unit.

The findings of this study are of potential practical as well as conceptual importance, particularly with the current shift to patient-centered care in all areas of medical care. Of the various models of the patient-physician relationship, Emanuel and Emanuel argue that the “deliberative model,” in which the patient’s perspective is incorporated when determining the preferred course of action, embodies the optimal patient-physician interaction. The results of this study could be used to make HPs and parents aware of the differences in preferences within and between groups. They further underscore the need for deliberations at an individual level in counseling future parents facing complex decisions about neonatal intensive care. The regional nature of our adolescent and parent subjects, the large sample size of the respondents, and the national input from neonatologists are strengths of our study findings, making them generalizable to the Canadian population. Whether these results are generalizable to other populations remains to be studied.

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10. The various models of the patient-physician relationship, Emanuel and Emanuel argue that the “deliberative model,” in which the patient’s perspective is incorporated when determining the preferred course of action, embodies the optimal patient-physician interaction.
DIFFERENCES IN PREFERENCES FOR NEO NATAL OUTCOMES


Though a little one, the master-word looms large in meaning. It is the open sesame to every portal, the great equalizer in the world, the true philosopher’s stone, which transmutes all the base metal of humanity into gold. . . . And the master-word is Work.
—Sir William Osler (1849-1919)