

Effects of Description of Options on Parental Perinatal Decision-Making

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KEY WORDS

decision-making, extreme prematurity, counseling, palliative care, intensive care

ABBREVIATIONS

CI—confidence interval
DR—delivery room
IC—intensive care
CC—comfort care
OR—odds ratio

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WHAT'S KNOWN ON THIS SUBJECT: Studies have found that the degree of detail with which palliative care is described and the order in which options are presented can affect end-of-life decisions. None of these studies, though, involved decisions regarding very premature infants.



WHAT THIS STUDY ADDS: Unlike other end-of-life decisions, those regarding extremely premature infants are influenced neither by the degree of detail nor order of presentation of management options. Deep-seated values embodied in the reasons given for these choices suggest why they are so robust.

abstract

OBJECTIVE: To examine whether parents' delivery room management decisions for extremely preterm infants are influenced by (1) the degree of detail with which options (comfort care [CC] or intensive care [IC]) are presented or (2) their order of presentation.

METHODS: A total of 309 volunteers, 18 to 55 years old, were each randomized to 1 of 4 groups: (1) detailed descriptions, CC presented first; (2) detailed descriptions, IC presented first; (3) brief descriptions, CC presented first; or (4) brief descriptions, IC presented first. Each received the description of a hypothetical delivery of a 23-week gestation infant and chose either IC or CC. Open-ended and structured questions elicited reasoning. Data were analyzed by χ^2 and logistic regression analysis.

RESULTS: Neither degree of detail, comparing groups 1+2 with 3+4 (37% vs 41%, odds ratio = 0.85, 95% confidence interval = 0.54–1.34, $P = .48$), nor order, comparing groups 1+3 with 2+4 (40% vs 37%, odds ratio = 0.88, 95% confidence interval = 0.56–1.39; $P = .59$), influenced the likelihood of choosing IC. Participants choosing IC were more likely to invoke sanctity of life and religiosity as personal values. Additional reasons for choosing IC were experiences with infants born at later gestational ages, giving the infant a chance, not watching their infant die, and equating CC with euthanasia. Some choosing CC wanted to avoid infant suffering.

CONCLUSIONS: The degree of detail and order of presentation had no effect on treatment decisions, suggesting that individuals bring well-articulated preexisting preferences to such decisions. Understanding beliefs and attitudes motivating these preferences can assist physicians in helping parents make informed decisions consistent with their values. *Pediatrics* 2012;129:891–902

Delivery room (DR) management decisions for infants born extremely preterm present ethically challenging and emotionally difficult decisions for parents and physicians. Some parents choose to resuscitate these infants and provide intensive care (IC) with no guarantees of survival or quality of life, whereas others opt for comfort care (CC). Professional organizations often advocate shared decision-making, involving parents and physicians, for preterm infants born at 23 to 24 weeks' gestation under conditions of clinical and ethical equipoise. Most studies of these decision-making processes have focused on physicians. The few studies of parents have found that ~60% choose to resuscitate and initiate IC regardless of the infant's gestational age or birth weight.^{1,2} The factors shaping these decisions remain largely unexplored.

A study by John and Fischhoff³ found that end-of-life palliative care for adults was more attractive when described more fully. Speculatively, more-detailed descriptions provide positive missing facts that make palliative care seem more like a treatment and less like "giving up." The current study examines whether similar effects are observed with decisions faced by parents with the prospect of delivery of an extremely preterm infant. We also examine whether choices between CC and IC are affected by a manipulation that provides no additional information: the order in which the options are presented. Studies in many domains have found that, when people are uncertain about their preferences, choices can be influenced by what they consider first and last.^{4,5}

METHODS

This institutional review board–exempt study used a 2 × 2 design, manipulating degree of detail and order of presentation for a realistically described, hypothetical case of the impending

delivery of an infant at 23 weeks' gestation. After reading an introductory paragraph describing the study, participants could opt to voluntarily participate by advancing to the next screen to begin the survey (see Appendix 1A, 1B). Each participant was randomized to 1 of the 4 groups described later in this article. Each survey began with the same short vignette describing the case in terms of both survival and mortality to avoid framing effects. The 2 treatment options were then described.

Degree of Detail Manipulation

Half of the participants first received the brief descriptions of the 2 treatment options, after which they chose either CC or IC and answered 4 open-ended questions regarding their reasoning, need for additional information, desire to consult people other than the physician, and other thoughts. They then received equally long detailed treatment descriptions, to avoid framing effects, after which they chose between the options again (Appendix 1A). The survey prevented respondents from returning to previous pages they had completed. The other participants received the same survey, but were asked to choose either CC or IC once, after having read both the brief and the detailed description consecutively. After their decision, they then answered the same 4 open-ended questions (Appendix 1B).

Order Manipulation

Half of the participants in each of the 2 groups received the IC description first; the other half received the CC description first.

Each group's survey concluded with demographic questions, including whether they had experience with prematurity and disability and their degree of religiousness (Appendix 2). The latter was evaluated with the Duke Religion Index Scale⁶; those whose responses

put them in categories 1 or 2 for each question were considered highly religious. Five-point Likert scales were used to elicit participants' judgments of the relative importance of sanctity of life and quality of life and relative preferences for paternalistic and autonomous decision-making styles.

Participants

Participants were recruited by e-mail from online pools maintained by qualtrics.com (Qualtrics, Inc). Randomization was computer generated on a secure server by using the Mersenne twister algorithm, a pseudorandomization number generator. There were no restrictions or blocking. Respondents older than 55 or younger than 18 were excluded to focus on participants of parenting age. Participants were paid \$7 for completing the survey, which was described as sponsored by the Division of Newborn Medicine at the University of Pittsburgh.

A sample of 300 was sought, affording a power of 80% with a *P* value of .05, to detect a difference as small as 16% between the proportions choosing the 2 options, estimating that 60% in 1 or the other group would choose IC (based on Streiner et al¹).

Comparisons of demographic variables among the 4 survey groups were made with analysis of variance for continuous variables, χ^2 tests for binary categorical variables, and Pearson correlations for nonbinary categorical variables. For purposes of subsequent analyses, the 2 survey groups in which participants received the brief descriptions before making a decision were combined and compared with the 2 survey groups in which participants received the detailed description of DR management options. This grouping evaluated the effect of detail on decisions. The 2 survey groups in which participants received information about CC first were combined and compared

with the 2 survey groups in which participants received information about IC first. This grouping evaluated the effect of order of presentation on decisions. Separate logistic regression analyses evaluated bivariate associations between choosing CC and preference for paternalistic decision-making and between choosing CC and favoring preservation of life. Multivariate logistic regression analyses incorporated all variables associated with the treatment decision that had $P < .10$ in bivariate analyses. Otherwise, $P < .05$ was the criterion for significance. An interaction term between detail and order was also included in the multivariate regression. Backward Wald elimination with all the variables was used to confirm this process. When they could be calculated, odds ratios (ORs) and 95% confidence intervals (CIs) are reported along with P values. All analyses were performed by using SPSS programs (SPSS Inc, Chicago, IL).

Qualitative responses to the open-ended questions were coded by emergent themes.⁷

RESULTS

Participants

A total of 458 individuals began the online survey. Eighty-two (18%) did not complete it. Of the remaining 376, 67 (18%) were excluded based on age. These rates were similar among the 4 groups. The final sample size was 309. The study was conducted and completed in the spring of 2009. Participants raised no comments or concerns. Overall, 39% of participants were men; 74% were white, 8% African American, 10% Hispanic, and 8% other; 64% were parents. Thirty-eight percent reported experiences with disability and 33% with prematurity. Almost all of these latter experiences were indirect, involving premature infants of family members or personal experiences with infants born at older gestational ages.

Only 1 participant reported having had an infant born at 24 weeks. Other reported experiences included term infants requiring IC and miscarriages. Twenty-nine percent of participants were classified as highly religious based on their responses to the Duke Religion Index Scale. Large majorities judged quality of life and preserving life to be equally important (Table 1) and preferred a shared decision-making style (Table 2).

There were no significant differences among the 4 groups in any of the demographics, except for racial distribution (Table 3); however, there were no significant differences on any demographic variables (including race) between the 2 groups that received the brief description and the 2 that received the detailed descriptions or between the 2 groups that received the choices in different order (data not shown).

Experimental Effects

Order had no effect on the proportion selecting CC, among those receiving brief descriptions (50.7% vs 49.3%, OR 1.16, 95% CI 0.63–2.2, $P = .63$) or detailed descriptions (51% vs 49%, OR 1.10, 95% CI 0.55–2.12, $P = .78$). Figure 1 depicts the treatment choices of participants as a function of the degree of detail provided. Approximately 60% chose IC whether they received the brief or detailed descriptions (OR 0.85, 95% CI 0.54–1.34, $P = .48$). Among participants who chose twice, first after reading the brief description and again after receiving the detailed description, only 4% changed their initial choice; all of them changed their choice from CC to IC.

Associations With the Choice

Participants were significantly less likely to choose CC if they were highly religious or valued preservation of life over quality of life (Table 4). These correlations remained significant in

TABLE 1 Participants' Judgments of the Relative Importance of Sanctity of Life and Quality of Life

| | |
|-----------------------------------------------------------------|-----|
| Quality of life is much more important than preserving life | 21% |
| Quality of life is somewhat more important than preserving life | 15% |
| Both quality of life and preserving life are equally important | 51% |
| Preserving life is somewhat more important than quality of life | 8% |
| Preserving life is much more important than quality of life | 4% |

TABLE 2 Participants' Preferences for Decision-Making Style

| | |
|----------------------------------------------------------------------------------|-----|
| I always prefer to have the doctor make medical decisions for me | 4% |
| I would prefer to have the doctor make medical decisions for me most of the time | 6% |
| I would prefer to make my medical decisions jointly with the doctor | 72% |
| I would prefer to make my own medical decisions most of the time | 11% |
| I always prefer to make my own decisions | 7% |

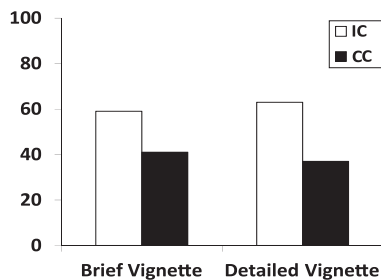
a multivariate model, including order of presentation, degree of detail, and an order \times detail interaction term (Table 5).

Qualitative Responses

Answers to the open-ended questions revealed several themes: (1) prematurity was rarely mentioned as a factor in decision-making by people who reported experience with it, possibly not differentiating outcomes at different gestational ages; (2) religious concerns were mentioned by equal portions (~10%) of participants who chose CC and IC; (3) CC was likened to euthanasia or assisted suicide by 17% of those who chose IC; (4) not wanting the responsibility for the decision or not being able to watch their infant die was mentioned by 60% of those choosing IC; (5) not having the infant suffer was mentioned by half of those choosing CC; (6) wanting more information about the care options was rarely mentioned by those who received the brief descriptions; and (7) 60% of the participants

TABLE 3 Demographics by Experimental Group

| | Brief/CC First (n = 90), % | Brief/IC First (n = 80), % | Detailed /CC First (n = 73), % | Detailed/ IC First (n = 66), % | P |
|-----------------------------|-------------------------------|-------------------------------|-----------------------------------|-----------------------------------|-----|
| Male | 44 | 36 | 40 | 40 | .75 |
| Race | | | | | .05 |
| White | 74 | 71 | 75 | 85 | |
| African American | 6 | 14 | 8 | 4 | |
| Hispanic | 11 | 6 | 8 | 11 | |
| Other | 9 | 9 | 8 | 0 | |
| Parent | 62 | 58 | 68 | 73 | .27 |
| Experience with disability | 55 | 34 | 38 | 38 | .75 |
| Experience with prematurity | 29 | 36 | 30 | 41 | .37 |
| Highly religious | 34 | 28 | 30 | 26 | .51 |

**FIGURE 1**

DR management decision as a function of amount of detail (brief versus detailed) provided about the options of CC or IC (% of participants).

wanted to ask family members, spouses, clergy, and/or to have additional medical opinions. The responses were often emotional, with many participants writing that this was an awful, difficult decision to have to make.

DISCUSSION

CC was chosen equally often whether it was described briefly or in detail, in both between-subject and within-subject comparisons. Only 4% of participants who made a decision based on a brief description chose differently after reading a detailed description. Participants' choices were unaffected by the order in which the 2 options were presented. Their qualitative answers were detailed, emotional, and thoughtful. Many made comments such as "this is the hardest decision to have to make," "[I] hope never to have to be in this situation," "what an awful decision," or "[I'm] filled with sadness." They seemed to understand the ethical issues and

make choices consistent with their values. For example, those who chose to initiate IC were much more likely to report being highly religious and to value the preservation of life over quality of life (also found by Haward et al²) compared with those choosing CC. They were sufficiently involved that very few participants would relinquish decision-making entirely to the physician, a result also reported by McHaffie et al.⁹ Many would leave the decision "up to God," typically choosing IC. Others would share the decisional dilemma with family members and clergy.

Thus, these choices were unaffected by manipulations that have proven powerful in other settings.³⁻⁵ Taken literally, these null effects could suggest that individuals have sufficiently well-articulated preferences regarding these choices; that they know what they want, even after receiving only the limited information in the brief descriptions. Once formed, those preferences are unaffected by additional information (the detail manipulation) or by a change in perspective (the order manipulation).

One possible explanation for our failure to find the kinds of context effects observed so widely in the literature is that, as with any null result, the design may have been too weak to reveal latent effects. For example, it is possible that even more detailed descriptions of the management options could have influenced the decision; however, in addition to having conventional statistical

power, our study seemed to evoke unusual participant involvement with its current stimuli. We speculate that the explanation lies in the subject matter. Studies finding context effects typically involve topics where respondents have uncertain preferences, allowing them to be influenced by contextual cues. Here, even the brief description evoked strong preferences. In the adult study involving end-of-life decisions,³ the brief descriptions might have evoked much weaker preferences, whereas the fuller description provided information and perspectives that changed how participants thought and felt. We speculate that even the brief description in the current study may have evoked strong preferences because the context of the decision involved the beginning of life or because the outcomes of the 2 options were more disparate in this study than in the adult study.³ In the adult study,³ death was most likely the ultimate outcome, regardless of the care option chosen. The lack of an order effect compared with studies in adults^{4,5} may also be explained by these context effects.

Stable preferences need not, however, be well-informed preferences. Some participants equated CC with assisted suicide. Others recounted stories of less premature infants who "did just fine," apparently not realizing the importance of those infants' greater gestational ages, despite our descriptions' emphasis on the unique problems of extreme prematurity. When individuals have such deep-seated misconceptions, communications may need to explain enough about neonatal development to afford them sound mental models for why gestational age matters so much, something that they may not grasp from statements about numbers of weeks alone.⁹⁻¹¹ The fact that participants reported being satisfied with the information that we provided in spite of these misconceptions suggests that

TABLE 4 Bivariate Relations of Variables to Choosing the CC Option

| Variable | OR | 95% CI | P |
|-------------------------------|-----------------|-----------|-------|
| Detailed description | 1.18 | 0.74–1.85 | .48 |
| IC presented first | 1.13 | 0.72–1.79 | .59 |
| Gender (male) | 1.11 | 0.68–1.77 | .66 |
| Age | 1.00 | 0.98–1.02 | .96 |
| Race | na ^a | | .95 |
| Parent | 0.89 | 0.55–1.44 | .65 |
| Experience with disability | 1.16 | 0.72–1.86 | .53 |
| Experience with prematurity | 1.09 | 0.67–1.76 | .75 |
| Highly religious | 0.34 | 0.19–0.59 | <.001 |
| Preferring paternalism | 0.86 | 0.64–1.15 | .32 |
| Favoring preservation of life | 0.31 | 0.23–0.42 | <.001 |

^a Not able to be calculated.

TABLE 5 Multivariate Relations of Variables to Choosing the CC Option

| Variable | OR | 95% CI | P |
|-------------------------------|------|-----------|-------|
| Detailed description | 0.77 | 0.35–1.68 | .51 |
| IC option first | 1.25 | 0.21–7.50 | .80 |
| Highly religious | 0.30 | 0.16–0.59 | <.001 |
| Favoring preservation of life | 0.31 | 0.23–0.42 | <.001 |
| Detailed × CC first | 0.86 | 0.29–2.56 | .79 |

they are unaware of such limits to their understanding. Our results raise the question of how well the (brief or detailed) descriptions offered in clinical practice inform parents. Opportunity samples such as ours provide a venue for identifying potential misconceptions and evaluating communications for addressing them, before they are used in clinical practice. People can make sound decisions only if they are well-enough informed about the facts of a choice and alternative ways to think about it such that further information and rumination will not affect their choices, nor will anything that they learn afterward make them wish that they had known or thought about it at the time.¹²

Limitations of our study include first that, although we screened our sample to focus on individuals who could theoretically encounter such decisions, hypothetical choices differ from actual ones, however intense research participants' involvement and however suddenly the actual decisions often arise for parents in extreme preterm

labor. Nonetheless, given the need to protect such parents, research with peers may provide suggestive results regarding problems and solutions. A second limitation to extrapolating from our experiment to clinical practice is that it did not offer the choice of initiating IC with continued reevaluation of that decision. The rationale for including this choice is sound; more information generally permits better decision-making. Within the context of our study, however, this option is not a decision, but a deferral of a decision. Because testing the effect of information detail and order of presentation of options required participants to make a decision, we restricted their choice options to 2 distinct courses of action. Given the differences between our results and previous ones, we hesitate to predict either the distribution of the choices in a study offering all 3 options or their sensitivity to context effects.

Third, we recognize that there are differences in the professional community regarding the prognosis that was provided in our vignette (eg, whether survival is possible at 22 weeks). The effects of different descriptions are empirical questions. Although we cannot predict how the choices would differ, our results lead us to predict that they would be equally stable with different orders of presentation and levels of detail.

Informed decision-making requires disclosure and comprehension of relevant

information, competence, and voluntariness.¹³ In adult clinical practice, informed consent has been under increased scrutiny, as research has shown patient comprehension to be poor, misunderstanding and mistaken beliefs frequent, and informed consent procedures and processes inadequate.^{14–17} Some have argued that presenting more detailed information may not necessarily result in better-informed choices.^{15–17} Our data support this. In neonatology, guidelines emphasize a shared decision-making process between parents and physicians to enable parents to make decisions consistent with their personal values while maintaining goals that are in the best interests of the infant.^{18–21} Survey research and self-reports in neonatology have shown variability in physician consultative styles, with inadequate exploration of parental values and decision-making preferences.^{22–28} Currently, much of what is communicated during the prenatal consultation is either at the discretion of the “expert” or based on suggested guidelines developed without parental input.^{29,30} Yet, parents and physicians frame decisions differently. Research in reproductive health decisions suggests that physicians approach decision-making from a medical frame, whereas patients approach it from a moral frame.³¹ This results in different informational needs and perceptions.^{22,28,31,32} Little is known about what information is relevant to parents, what factors influence parental decisions, and how the medical community can most effectively participate in the decision-making process. The current study only begins to explore some of these issues. More research evaluating the informed consent process from the perspective of the parents is required.

CONCLUSIONS

These results suggest 3 important practical implications. First, parents

need to be involved in care decisions for extremely preterm infants, given how diverse their preferences and perspectives are.^{20,33,34} Their disagreements parallel those among medical professionals. Reasonable people may choose different options for DR management of their extremely premature infant. Second, this decision process might be improved if physicians were better able to identify the information

that parents want and need. When decisions evoke strong values (religiosity, preferences for preservation of life, prevention of suffering), parents need the information most relevant to those values, conveyed in ways that ensure their understanding (eg, about the nature of the ICU experience or the importance of gestational age), recognizing that irrelevant or incomprehensible information may needlessly

confuse or distress them.¹⁷ More research is needed to formulate strategies that best elicit what information and how much is most important to parents. Third, it is important to understand what parents' preexisting preferences are and on what beliefs and values these preferences are based so that misconceptions can be dispelled and parents can make decisions consistent with their values.

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APPENDIX 1A

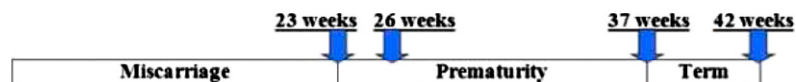
Welcome!

We invite you to complete this survey asking how people perceive delivery room treatment options for infants born extremely premature.

We are surveying individuals at least 18 years of age in the United States. If you choose to participate, you will read a paragraph describing prematurity, then give your opinions about those treatments. The survey will last approximately 10 minutes and include a total of 13 questions designed as multiple-choice, opinion, and demographic questions.

The survey has no foreseeable risks, although you may feel some psychological discomfort in thinking about decisions for extremely preterm infants. This is an entirely anonymous questionnaire and so your responses will never be linked to you. All results will be kept in a separate database from your personal information and your personal information will not be linked to your survey responses in any way. Your participation is entirely voluntary and you may choose to withdraw from the study at any time. This study is being conducted by Dr Haward, who can be reached at hawardm@mail.magee.edu with any questions or concerns.

NORMALLY A PREGNANCY LASTS 37-42 WEEKS. WHEN INFANTS ARE BORN BEFORE 23 WEEKS OF GESTATION, IN GENERAL NOTHING CAN BE DONE TO SAVE THEM AND THE PREGNANCIES END IN MISCARRIAGES. MODERN MEDICINE HAS VERY GOOD SUCCESS WITH THOSE WHO ARE AT LEAST 26 WEEKS OLD.



THOSE BORN AT 23 WEEKS POSE A SERIOUS DECISION FOR THEIR PARENTS. UNLESS THEY RECEIVE IMMEDIATE INTENSIVE CARE, THEY DIE.

SOME PARENTS CHOOSE A TREATMENT OPTION, CALLED *COMFORT CARE*, WHERE EVERYTHING POSSIBLE IS DONE TO ENSURE THE INFANT A DIGNIFIED, PAIN-FREE DEATH, IN THEIR PARENTS' ARMS.

OTHER PARENTS CHOOSE A TREATMENT OPTION CALLED, *INTENSIVE CARE*. INFANTS RECEIVING INTENSIVE CARE MAY STILL DIE. THOSE WHO SURVIVE MAY SUFFER LIFE-LONG DISABILITIES. THEIR CHANCES DEPEND ON SEVERAL FACTORS, MOST CRITICALLY, HOW OLD THEY ARE WHEN THEY ARE BORN.

WE WILL NOW DESCRIBE THE DIFFICULT DECISION FACING ONE SET OF PARENTS, THEN ASK WHAT YOU THINK THAT YOU WOULD DO, IN THEIR SITUATION.

IMAGINE THAT YOU (OR YOUR PARTNER) SUDDENLY EXPERIENCE PRETERM LABOR, AFTER 23 WEEKS OF A PREGNANCY THAT HAS SEEMED NORMAL. AFTER A THOROUGH EXAMINATION, YOUR DOCTOR TELLS YOU THAT YOUR BABY WILL BE BORN IN THE NEXT COUPLE OF HOURS.

SHE THEN DESCRIBES YOUR OPTIONS, *COMFORT CARE* OR *INTENSIVE CARE*.

SHE SAYS THAT WITH *COMFORT CARE*, YOU WOULD HOLD YOUR BABY AND YOUR BABY WOULD DIE WITHOUT PAIN IN YOUR ARMS.

WITH *INTENSIVE CARE*, YOUR BABY WOULD HAVE A 25% CHANCE OF LIVING AND A 75% CHANCE OF DYING. THAT IS, AMONG 100 BABIES IN SIMILAR SITUATIONS, ABOUT 25 LIVE AND 75 DIE. BABIES WHO LIVE TYPICALLY SPEND 4-5 MONTHS IN INTENSIVE CARE. AMONG THE 25 WHO LIVE, 10 WILL HAVE SEVERE DISABILITIES LIKE MENTAL RETARDATION, BLINDNESS, DEAFNESS OR CEREBRAL PALSY AND 15 WILL HAVE EITHER MILD DISABILITIES OR MAY HAVE NO DISABILITY. YOUR DOCTOR CANNOT GIVE YOU ANY BETTER INFORMATION.

THE CHART SHOWS WHAT TO EXPECT, AMONG 100 BABIES LIKE YOURS.

| COMFORT CARE | INTENSIVE CARE | | |
|--------------|----------------|----------------------|--------------------------|
| DIE | DIE | SEVERE DISABILITY | MILD OR NO DISABILITY |
| 100 | 75 | 10 | 15 |

THUS, YOU CAN CHOOSE EITHER COMFORT CARE OR INTENSIVE CARE FOR YOUR BABY. PLEASE INDICATE WHICH OPTION YOU WOULD CHOOSE:

COMFORT CARE

INTENSIVE CARE

Please explain why you chose that option. Please give as much or as little detail as you wish.

Is there any other information that would have helped you to make your decision? Please specify in as much or as little detail as you wish.

Is there someone else you would like to speak with before making this decision? Please specify.

What else is going through your mind, when you think about this situation?

HERE IS SOME ADDITIONAL INFORMATION ABOUT THE OPTIONS, WHICH WOULD BE AVAILABLE TO ACTUAL PARENTS, IF THEY WANTED TO KNOW MORE ABOUT THE DETAILS.

COMFORT CARE

IF YOU CHOOSE COMFORT CARE, AS SOON AS YOUR BABY IS BORN, DOCTORS WILL BEGIN TREATMENTS TO MAKE YOUR BABY FEEL AS COMFORTABLE AS POSSIBLE. THESE TREATMENTS INCLUDE MAKING SURE YOUR BABY IS COMFORTABLE IMMEDIATELY AFTER BIRTH BY DRYING YOUR BABY, KEEPING YOUR BABY WARM IN BLANKETS AND GIVING YOUR BABY PAIN MEDICINE, IF YOU OR THE BABY'S DOCTOR THINKS YOUR BABY IS SUFFERING. OTHER TREATMENTS MAY INCLUDE OXYGEN NEAR YOUR BABY'S NOSE OR FEEDING YOUR BABY BY MOUTH. YOUR BABY WILL NOT RECEIVE ANY IV'S OR ANY OTHER TREATMENTS THAT COULD CAUSE PAIN. YOUR BABY CAN EITHER STAY WITH YOU OR CAN BE ADMITTED TO THE NURSERY. YOU WILL BE ABLE TO HOLD YOUR BABY AS LONG AS YOU WANT. SOMETIMES BABIES DIE MINUTES AFTER BIRTH, SOMETIMES IT TAKES A COUPLE OF HOURS, AND SOMETIMES BABIES LIVE FOR MORE THAN A DAY. HOWEVER, ALL BABIES RECEIVING COMFORT CARE DO DIE. DOCTORS AND NURSES WILL BE CARING FOR YOUR BABY UNTIL THEN.

INTENSIVE CARE

IF YOU CHOOSE INTENSIVE CARE, AS SOON AS YOUR BABY IS BORN, DOCTORS WILL BEGIN TREATMENTS TO TRY TO ENSURE THAT YOUR BABY STAYS ALIVE. ONE COMMON TREATMENT

IS HELPING THE BABY TO BREATHE, BY INSERTING A TUBE FROM THE MOUTH TO THE LUNGS. THE TUBE IS ATTACHED TO A MACHINE CALLED A VENTILATOR, WHICH ARTIFICIALLY BREATHES FOR YOUR BABY. SOME BABIES NEED CHEST COMPRESSIONS, WHERE THE DOCTOR PUSHES ON THE BABY'S CHEST TO GET THE HEART BEATING FAST ENOUGH. DOCTORS TRY TO CONTROL PAIN, BUT THE MAIN GOAL IS SURVIVAL. IF THEY ARE SUCCESSFUL, THEN YOUR BABY WILL BE ADMITTED TO THE INTENSIVE CARE UNIT. THERE, YOUR BABY WILL RECEIVE TESTS AND TREATMENTS, INCLUDING IVS FOR NUTRITION, BLOOD TESTS AND X-RAYS. YOUR BABY MIGHT ALSO RECEIVE MEDICATIONS FOR INFECTIONS, BLOOD TRANSFUSIONS, AND SURGERY FOR INTESTINAL OR HEART PROBLEMS. YOU MAY NOT BE ABLE TO HOLD YOUR BABY FOR SEVERAL WEEKS, BUT CAN BE CLOSE BY ALMOST ALL OF THE TIME. BABIES WHO DO WELL TYPICALLY STAY IN THE INTENSIVE CARE UNIT FOR AT LEAST 5 MONTHS; BABIES WHO ARE SICKER MAY STAY LONGER OR MAY DIE. DOCTORS AND NURSES WILL BE THERE UNTIL YOUR BABY GOES HOME OR DIES.

AFTER HAVING CONSIDERED THIS INFORMATION, PLEASE INDICATE WHICH OPTION YOU WOULD CHOOSE:

COMFORT CARE

INTENSIVE CARE

APPENDIX 1B

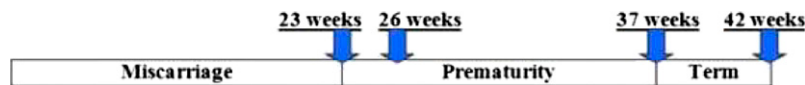
Welcome!

We invite you to complete this survey asking how people perceive delivery room treatment options for infants born extremely premature.

We are surveying individuals at least 18 years of age in the United States. If you choose to participate, you will read a paragraph describing prematurity, then give your opinions about those treatments. The survey will last approximately 10 minutes and include a total of 13 questions designed as multiple-choice, opinion, and demographic questions.

The survey has no foreseeable risks, although you may feel some psychological discomfort in thinking about decisions for extremely preterm infants. This is an entirely anonymous questionnaire and so your responses will never be linked to you. All results will be kept in a separate database from your personal information and your personal information will not be linked to your survey responses in any way. Your participation is entirely voluntary and you may choose to withdraw from the study at any time. This study is being conducted by Dr Haward, who can be reached at hawardm@mail.magee.edu with any questions or concerns.

NORMALLY A PREGNANCY LASTS 37-42 WEEKS. WHEN INFANTS ARE BORN BEFORE 23 WEEKS OF GESTATION, IN GENERAL NOTHING CAN BE DONE TO SAVE THEM AND THE PREGNANCIES END IN MISCARRIAGES. MODERN MEDICINE HAS VERY GOOD SUCCESS WITH THOSE WHO ARE AT LEAST 26 WEEKS OLD.



THOSE BORN AT 23 WEEKS POSE A SERIOUS DECISION FOR THEIR PARENTS. UNLESS THEY RECEIVE IMMEDIATE INTENSIVE CARE, THEY DIE.

SOME PARENTS CHOOSE A TREATMENT OPTION, CALLED *COMFORT CARE*, WHERE EVERYTHING POSSIBLE IS DONE TO ENSURE THE INFANT A DIGNIFIED, PAIN-FREE DEATH, IN THEIR PARENTS' ARMS.

OTHER PARENTS CHOOSE A TREATMENT OPTION CALLED, *INTENSIVE CARE*. INFANTS RECEIVING INTENSIVE CARE MAY STILL DIE. THOSE WHO SURVIVE MAY SUFFER LIFE-LONG DISABILITIES. THEIR CHANCES DEPEND ON SEVERAL FACTORS, MOST CRITICALLY, HOW OLD THEY ARE WHEN THEY ARE BORN.

WE WILL NOW DESCRIBE THE DIFFICULT DECISION FACING ONE SET OF PARENTS, THEN ASK WHAT YOU THINK THAT YOU WOULD DO, IN THEIR SITUATION.

IMAGINE THAT YOU (OR YOUR PARTNER) SUDDENLY EXPERIENCE PRETERM LABOR, AFTER 23 WEEKS OF A PREGNANCY THAT HAS SEEMED NORMAL. AFTER A THOROUGH EXAMINATION, YOUR DOCTOR TELLS YOU THAT YOUR BABY WILL BE BORN IN THE NEXT COUPLE OF HOURS.

SHE THEN DESCRIBES YOUR OPTIONS, *COMFORT CARE* OR *INTENSIVE CARE*.

SHE SAYS THAT WITH *COMFORT CARE*, YOU WOULD HOLD YOUR BABY AND YOUR BABY WOULD DIE WITHOUT PAIN IN YOUR ARMS.

WITH *INTENSIVE CARE*, YOUR BABY WOULD HAVE A 25% CHANCE OF LIVING AND A 75% CHANCE OF DYING. THAT IS, AMONG 100 BABIES IN SIMILAR SITUATIONS, ABOUT 25 LIVE AND 75 DIE. BABIES WHO LIVE TYPICALLY SPEND 4-5 MONTHS IN INTENSIVE CARE. AMONG THE 25 WHO LIVE, 10 WILL HAVE SEVERE DISABILITIES LIKE MENTAL RETARDATION, BLINDNESS, DEAFNESS OR CEREBRAL PALSY AND 15 WILL HAVE EITHER MILD DISABILITIES OR MAY HAVE NO DISABILITY. YOUR DOCTOR CANNOT GIVE YOU ANY BETTER INFORMATION.

THE CHART SHOWS WHAT TO EXPECT, AMONG 100 BABIES LIKE YOURS.

| COMFORT CARE | INTENSIVE CARE | | |
|--------------|----------------|----------------------|--------------------------|
| DIE | DIE | SEVERE DISABILITY | MILD OR NO DISABILITY |
| 100 | 75 | 10 | 15 |

THUS, YOU CAN CHOOSE EITHER COMFORT CARE OR INTENSIVE CARE FOR YOUR BABY.

HERE IS SOME MORE INFORMATION ABOUT THE TWO OPTIONS.

COMFORT CARE

IF YOU CHOOSE COMFORT CARE, AS SOON AS YOUR BABY IS BORN, DOCTORS WILL BEGIN TREATMENTS TO MAKE YOUR BABY FEEL AS COMFORTABLE AS POSSIBLE. THESE TREATMENTS INCLUDE MAKING SURE YOUR BABY IS COMFORTABLE IMMEDIATELY AFTER BIRTH BY DRYING YOUR BABY, KEEPING YOUR BABY WARM IN BLANKETS AND GIVING YOUR BABY PAIN MEDICINE, IF YOU OR YOUR BABY'S DOCTOR THINKS YOUR BABY IS SUFFERING. OTHER TREATMENTS MAY INCLUDE OXYGEN NEAR YOUR BABY'S NOSE OR FEEDING YOUR BABY BY MOUTH. YOUR BABY WILL NOT RECEIVE ANY IV'S OR ANY OTHER TREATMENTS THAT COULD CAUSE PAIN. YOUR BABY CAN EITHER STAY WITH YOU OR CAN BE ADMITTED TO THE NURSERY. YOU WILL BE ABLE TO HOLD YOUR BABY AS LONG AS YOU WANT. SOMETIMES BABIES DIE MINUTES AFTER BIRTH, SOMETIMES IT TAKES A COUPLE OF HOURS, AND SOMETIMES BABIES LIVE FOR MORE THAN A DAY. HOWEVER, ALL BABIES RECEIVING COMFORT CARE DO DIE. DOCTORS AND NURSES WILL BE CARING FOR YOUR BABY UNTIL THEN.

INTENSIVE CARE

IF YOU CHOOSE INTENSIVE CARE, AS SOON AS YOUR BABY IS BORN, DOCTORS WILL BEGIN TREATMENTS TO TRY TO ENSURE THAT YOUR BABY STAYS ALIVE. ONE COMMON TREATMENT IS HELPING THE BABY TO BREATHE, BY INSERTING A TUBE FROM THE MOUTH TO THE LUNGS. THE TUBE IS ATTACHED TO A MACHINE CALLED A VENTILATOR, WHICH ARTIFICIALLY BREATHES FOR YOUR BABY. SOME BABIES NEED CHEST COMPRESSIONS, WHERE THE DOCTOR PUSHES ON THE BABY'S CHEST TO GET THE HEART BEATING FAST ENOUGH. DOCTORS TRY TO CONTROL PAIN, BUT THE MAIN GOAL IS SURVIVAL. IF THEY ARE SUCCESSFUL, THEN YOUR BABY WILL BE ADMITTED TO THE INTENSIVE CARE UNIT. THERE, YOUR BABY WILL RECEIVE TESTS AND TREATMENTS, INCLUDING IV'S FOR NUTRITION, BLOOD TESTS AND X-RAYS. YOUR BABY MIGHT ALSO RECEIVE MEDICATIONS FOR INFECTIONS, BLOOD TRANSFUSIONS, AND SURGERY FOR INTESTINAL OR HEART PROBLEMS. YOU MAY NOT BE ABLE TO HOLD YOUR BABY FOR SEVERAL WEEKS, BUT CAN BE CLOSE BY ALMOST ALL OF THE TIME. BABIES WHO DO WELL TYPICALLY STAY IN THE INTENSIVE CARE UNIT FOR AT LEAST 5 MONTHS; BABIES WHO ARE SICKER MAY STAY LONGER OR MAY DIE. DOCTORS AND NURSES WILL BE THERE UNTIL YOUR BABY GOES HOME OR DIES.

AFTER HAVING CONSIDERED THIS INFORMATION, PLEASE INDICATE WHICH OPTION YOU WOULD CHOOSE:

COMFORT CARE

INTENSIVE CARE

Please explain why you chose that option. Please give as much or as little detail as you wish.

Is there any other information that would have helped you to make your decision? Please specify in as much or as little detail as you wish.

Is there someone else you would like to speak with before making this decision? Please specify.

What else is going through your mind, when you think about this situation?

APPENDIX B

In making medical decisions:

- I always prefer to have the doctor make medical decisions for me
- I would prefer to have the doctor make medical decisions for me most of the time
- I would prefer to make my medical decisions jointly with the doctor
- I would prefer to make my own medical decisions most of the time
- I always prefer to make my own decisions

In making end-of-life decisions:

- Quality of life is much more important than preserving life
- Quality of life is somewhat more important than preserving life
- Both quality of life and preserving life are equally important
- Preserving life is somewhat more important than quality of life
- Preserving life is much more important than quality of life

Please check all that apply

- I have had previous experience with prematurity
- I have had previous experience with disability
- I have one or more children

Please indicate your gender

- Male
- Female

Please tell us your age

Please tell us your race (check all that apply):

- Asian
- Black or African American
- Hispanic, Latino or Latina
- Native American
- White or Caucasian
- Other

Please rate the extent to which you agree with the following statements:

| | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly Disagree |
|---------------------------------------------------------------------------------------------------------------------|----------------|-------|----------------------------|----------|-------------------|
| My religious beliefs are what really lie behind my whole approach to life | | | | | |
| I spend time in private religious activities such as prayer, meditation, or religious readings at least once a week | | | | | |
| I try hard to carry religion over into all other dealings in life | | | | | |
| In my life I experience the presence of the divine | | | | | |
| I attend religious meetings or services at least once a week | | | | | |