

Values Parents Apply to Decision-Making Regarding Delivery Room Resuscitation for High-Risk Newborns

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What's Known on This Subject

Many parents of high-risk newborns desire to collaborate with physicians in decision-making regarding resuscitation. Physicians emphasize cognitive information when counseling families in such situations. What information parents find to be most helpful during decision-making is not clear.

What This Study Adds

Parents report that religion, spirituality, and hope, not physicians' predictions about morbidity and death, are central to their decision-making. Parents in these situations feel abandoned without physician hope and compassion.

ABSTRACT

OBJECTIVE. The aim of this study was to characterize parental decision-making regarding delivery room resuscitation for infants born extremely prematurely or with potentially lethal congenital anomalies.

METHODS. This was a qualitative multicenter study. We identified English-speaking parents at 3 hospitals whose infants had died as a result of extreme prematurity or lethal congenital anomalies in 1999–2005. Parents were interviewed about their prenatal decision-making. Maternal medical charts were reviewed for documented discussions regarding delivery room resuscitation. Subject enrollment was stopped when saturation of themes was achieved.

RESULTS. Twenty-six mothers of infants were interviewed. All parents wanted to participate to some degree in decisions regarding delivery room resuscitation. Few parents recalled discussing options for delivery room resuscitation with physicians, and even fewer recalled being offered the option of comfort care, even when these discussions were documented in the medical chart. Parents did not report physicians' predictions of morbidity and death to be central to their decision-making. Religion, spirituality, and hope guided decision-making for most parents. Some parents felt that they had not made any decisions regarding resuscitation and instead "left things in God's hands." These parents typically were documented by staff members to "want everything done."

CONCLUSIONS. The values that parents find most important during decision-making regarding delivery room resuscitation may not be addressed routinely in prenatal counseling. Parents and physicians may have different interpretations of what is discussed and what decisions are made. Future work should investigate whether physicians can be trained to address effectively parents' values during the decision-making process and whether addressing these values may improve physician-parent communication and lead to better postdecision outcomes for parents. *Pediatrics* 2008;122:583–589

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Key Words

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WHEN AN INFANT is likely to be born extremely prematurely or with potentially lethal anomalies, it can be difficult for physicians to predict for parents whether the infant will survive intact, survive with severe disability, or die soon after delivery. Because of this uncertainty, several management options are considered medically, ethically, and legally reasonable in the delivery room, ranging from aggressive resuscitation to compassionate care only.¹ The medical uncertainty in these scenarios and the long-term emotional and spiritual effects on the family suggest that collaboration between physicians and parents during decision-making is imperative.^{2,3} The American Academy of Pediatrics, Committee on Fetus and Newborn, emphasizes the importance of incorporating parents' values into decision-making,¹ but the values that parents apply to decisions regarding delivery room resuscitation have not been well described. In other areas of pediatrics, physicians have been shown to be poor judges of family preferences.⁴⁻⁶

Time pressures, medical urgency, and lack of relationships between physicians and parents in many of these scenarios preclude comprehensive conversations, requiring physicians to prioritize which essential information to

relay to and to seek from parents. When time for decision-making is limited, collaboration might be enhanced if physicians were better able to focus discussions on the values that families in similar scenarios found to be most important.

There were 3 aims in the current study. The first was to characterize the values that parents apply to decision-making regarding delivery room resuscitation for high-risk infants. The second was to describe parents' recall of their discussions with physicians regarding delivery room resuscitation. The third was to identify what parents most want from physicians as they make decisions regarding delivery room resuscitation in the context of a high-risk pregnancy.

METHODS

Participants and Design

A qualitative multicenter study was conducted at 2 urban, regional, referral centers and 1 suburban community hospital. Human subjects research approval was obtained at all 3 sites. Medical charts were used to identify infants who died between 1999 and 2005 as a result of extreme prematurity, defined as gestational age of 22^{0/7} to 25^{6/7} weeks, or a lethal congenital anomaly, such as severe congenital diaphragmatic hernia or hypoplastic left heart syndrome.

Parents of these infants were contacted by mail no less than 9 months after the deaths of their infants. Institutional review boards at 2 sites approved an "opt-out" recruitment strategy; eligible subjects received an introductory letter with a postcard to return if they wished to decline further contact. Subjects who returned no postcard were invited by telephone to participate in an audiotaped interview. The third institutional review board required an "opt-in" recruitment strategy; eligible subjects received an introductory letter and consent form that needed to be returned to permit additional contact.

Questionnaire and Data Collection

A semi-structured interview instrument was designed on the basis of a literature review and discussions with experts in neonatology and pediatric palliative care.⁷⁻⁹ Questions focused on the information parents remembered receiving during pregnancy about the fetal complications, their discussions with physicians regarding delivery room resuscitation options, and the values on which parents relied during decision-making. The instrument was pilot tested with parents who had experienced previous infant losses, with respect to wording, content, cognitive validity, and parents' willingness to participate; on the basis of their responses, the instrument was revised. All parents were given the option to complete the interview face to face or by telephone. One interviewer (Dr Boss) had formal training in conducting semi-structured interviews and trained the other 2 interviewers (Dr Donohue and Ms Sulpar). The interviewers jointly reviewed all pilot interviews and 2 initial subject interviews for further conformity with interview style and prompts. Maternal medical charts were re-

viewed for documented discussions of fetal viability and delivery room resuscitation options.

Data Analyses

Simultaneously with subject recruitment, completed interviews were coded for content independently by the 3 reviewers (Drs Boss and Donohue and Ms Sulpar). Content codes were reviewed with the lead analyst (Ms West), and discrepancies were resolved through repeated discussion. Key themes were identified on the basis of the frequency with which they were raised in individual interviews. When no new thematic content was found in the interviews, subject recruitment ceased. This process, called thematic saturation, is a well-described qualitative method to avoid an unnecessarily large and repetitive data set.¹⁰⁻¹² Saturation typically occurs more rapidly in research designed to describe beliefs and perceptions among people with shared experiences than in studies that seek to demonstrate differences between groups.¹⁰ Quantitative data were entered into SPSS 13.0 (SPSS, Chicago, IL) to generate descriptive frequencies.

RESULTS

Study Group

Twenty-six mothers were interviewed; 25 chose to be interviewed by telephone, and 1 hearing-impaired mother completed the interview via e-mail. Between 10 months and 5 years had elapsed between the time of the infant's death and the interview, with a median of 3 years.

Study population demographic characteristics are presented in Table 1. Subjects from the 3 sites were generally similar, although rates of assisted reproduction were lower at 1 site than at the other 2 sites (0% vs 13% and 27%). Comparisons of subjects with nonresponders were not possible, because the opt-in strategy precluded identification of which patients refused to participate and which were not located.

TABLE 1 Demographic Features of the Study Population

	<i>n</i> (%)
Diagnosis	
Extremely premature	13 (50)
Major anomaly	13 (50)
Maternal age	
<25 y	7 (27)
25-35 y	11 (42)
>35 y	8 (31)
Maternal race	
White	16 (62)
Black/other	10 (38)
Maternal education	
Any college	19 (73)
High school or less	7 (27)
Previous birth	
Preterm	2 (8)
Term	10 (38)
Previous miscarriage/loss	14 (54)
Assisted reproduction	4 (15)

Most subjects had ≥ 7 days between the diagnosis of a pregnancy problem and delivery. Four primary themes characterizing parental experiences of decision-making regarding delivery room resuscitation were identified, that is, (1) perception of resuscitation options, (2) consideration of physicians' predictions, (3) reliance on religion, spirituality, and hope, and (4) desire for physician hope and compassion, regardless of the predicted neonatal outcome.

Parents Rarely Perceive That There Are Options for Delivery Room Resuscitation

All parents wanted to participate to some degree in decision-making regarding delivery room resuscitation. Most parents wanted to decide with physicians, whereas some wanted to decide alone. Despite desiring to participate in decision-making and having spoken with ≥ 1 physician about the high-risk pregnancy, few parents recalled discussing options for delivery room resuscitation. Even fewer recalled discussing compassionate care. White women were less likely than black women or other minority women to recall discussing compassionate care with physicians.

"I specifically remember that we were not asked to make decisions."

"I think it seemed to me it was more so I was given this is what could happen in the NICU and what would probably happen. It was not so much a decision but more so information."

"No one brought up [the possibility of not resuscitating], just my husband and I [discussed it]."

Maternal medical charts revealed a different perspective about these discussions. For example, one parent stated in the interview, "They said because of the age < 24 weeks [gestation], nothing would be done." The physician documented in the medical chart, "... we discussed at length various options."

Parents had better recall of discussing obstetric options, such as whether to proceed with cesarean section because of fetal distress. Most parents felt that they had participated in decision-making regarding delivery room resuscitation, whether they recalled discussing infant resuscitation options.

Physicians' Predictions of Morbidity and Death Are Not Central to Parental Decision-making Regarding Delivery Room Resuscitation

Most parents felt that their decisions regarding delivery room resuscitation were not affected by physicians' typically grim predictions regarding the infant's possibility of survival or disability. In contrast, parents were influenced by their own sense of the possibility of survival or disability, which was nearly uniformly positive. Parents described several reasons why physicians' predictions were not central to their decision-making, including difficulty understanding the information, feeling emotionally overwhelmed, and enduring their own medical crises.

"The doctor listed all of these dire things that could happen but I could swear they said the survival rate was 100%. Maybe I heard it wrong, maybe I just latched

onto it because it was what I wanted to hear. Finally I said, 'Do you mean he could die?' and he said, 'Yes,' and it was the first time I had any idea that that could happen."

"I mean they were great doctors and nurses but I really can't remember what was discussed because I was scared. I knew she was going to pass away but I still had a glimmer of hope. I'm sure they did discuss genetic things but I was in the mindset where I didn't want to hear that because everything is going to be okay."

"[The doctors] told me lots of things that I wasn't really sure about. I was in a lot of pain and things started to happen, like I couldn't see things. I was trying to take things in and at the same time find a way to stay alive."

Religion, Spirituality, and Hope Are the Primary Values That Parents Apply to Decision-making Regarding Delivery Room Resuscitation

Religion, spirituality, and hope guided most parents' decision-making. Regardless of the medical information, parents maintained hope that everything would be fine. They were encouraged by friends and family members to pray for miracles, to transfer to a hospital thought capable of miracles, or to trust that a miracle would happen despite the physicians. Some parents felt that there were no decisions to make regarding delivery room resuscitation; they wanted the physicians to do everything they could, and the rest was "in God's hands."

"I could not be the one to decide if God chooses to take the baby away at this time or just let it run its course." (This infant was diagnosed prenatally as having trisomy 18; the mother requested a cesarean section because of fetal distress and surgical repair of the infant's ventricular septal defect.)

"When they told me they thought she was not going to survive, I put it in God's hands. God had made her into a baby, and if I had made it that far [with the pregnancy], it was up to Him."

"You know everyone told me don't worry about what [the doctors] say, she will make it, she's a miracle. And so that's pretty much all I heard."

"There was a lady who said, 'You know this child has all of these problems, why are you going to bring him into the world? Are you looking for God to step in?' I said, 'Well, as a matter of fact, I am.' If you think God is going to come in and perform a miracle, you have a right to do that."

Parents Feel Abandoned Without Physician Hope and Compassion

Parents explained that what they needed most from health care providers was compassion and hope that the infant could survive. Women mistrusted physicians who communicated only negative information and seemed to have "given up." Although all parents received bad news from physicians, physicians who expressed emotion were perceived to be more compassionate and hopeful. Parents felt abandoned by physicians who seemed untouched by the grief of the experience or who appeared to be "following protocol" or "acting by the book." Par-

ents described these interactions as motivating them to advocate for their baby “against” the health care team.

“I felt that they could have had a little more compassion instead of being so negative, especially when a hospital is known for good research and good procedures and stuff. Just be more optimistic. It’s really important for a parent to hear some hope, although the rationale says that this is 90% going to happen this way negatively.”

“I didn’t trust the physicians. Every time I talked with them it was always negative. I needed some compassion. I would ask the nurse if she agreed with the physician’s statements.”

“One physician kept wanting to induce me earlier and earlier. She kept saying this pregnancy is not a good one and stuff and shortly after the baby was born she came up to me and wanted to do an autopsy and that was not going to happen. I mean, had she let me grieve for longer than 20 minutes I might have let something happen as far as the autopsy, but I didn’t want that woman coming anywhere near my child at that point.”

DISCUSSION

Mothers participating in this study described religion, spirituality, hope, and compassion as being the most important values they considered when making decisions regarding delivery room resuscitation for infants born extremely prematurely or with lethal congenital anomalies. Physicians’ predictions regarding morbidity and death had less influence on parents’ decision-making. Most mothers could not recall discussing specific options for delivery room resuscitation with physicians.

Physicians and parents may have different perceptions of discussions regarding delivery room resuscitation because they are, in effect, speaking different languages. Neonatologists have been shown to emphasize predictions of morbidity and death when counseling families, with less attention to the emotional and spiritual concerns of parents.^{13–15} Parents in our study told us that, although they often heard the medical information, the conclusions they drew about what should be done in the delivery room were based on their own emotions and on their struggle to make sense of the experience in light of their views regarding life and God. Because religiosity and belief in divine intervention have been associated with wanting all measures to extend life, addressing parents’ religious and spiritual concerns early, as they relate to decisions regarding delivery room resuscitation, may enhance communication and understanding between parents and physicians.^{16,17} Whether a multidisciplinary approach to prenatal counseling that incorporates religious personnel could enhance this process deserves investigation.

Parents’ desire to proceed with delivery room resuscitation often was based on their own hope that the infant could survive intact, despite physicians’ predictions of disability and death. Fifteen percent of the mothers in our study had conceived through artificial reproduction, and 54% had experienced previous miscarriages or infant deaths. These women described being very emotionally invested in having a baby despite the odds. Freda et al¹⁸

found that women undergoing assisted reproduction often hope that a new pregnancy will lessen the grief from previous losses. Given that women who deliver infants prematurely or with major congenital anomalies have increased odds of having another high-risk pregnancy, acknowledging this compounded grief might yield a more complete discussion of the parents’ motivations and values with regard to the current pregnancy.

Parents in our study needed physicians to convey hope and compassion when discussing delivery room resuscitation options, even when the infant’s outcome was likely to be poor. Physicians who were perceived as providing more hope were not necessarily more likely to predict survival; in fact, some of the physicians whom parents described as hopeful predicted nearly certain death. These physicians gave parents hope because they expressed emotion and showed the parents that they were touched by the tragedy of the situation. Other authors have explored how patients with a terminal diagnosis feel that physicians can promote hope.^{19,20} Important elements include providing emotional support, respecting denial as a coping mechanism, and shifting the focus of hope to what can be realistically achieved, compared with what can be wished for but never achieved. For a neonatologist engaged with a family in prenatal counseling, this might mean openly acknowledging the grief and pain of the situation, reassuring the family that the staff members join in their hope that the infant’s outcome will be a good one, and helping the parents imagine how they might want events to proceed if the outcome is death or severe disability.

Expressing their own emotions during intense patient interactions can be uncomfortable for physicians.^{21–23} Nevertheless, there is evidence that parents value physicians’ emotional reactions when the physicians communicate bad news.^{24–26} Parents in our study were touched when physicians were visibly saddened by the events, and the parents felt a deeper sense of trust that the physicians would make decisions in the best interest of the family. It is concerning that some aspects of medical training and practice have been shown to suppress physicians’ empathy.^{27–30} Physician training programs that emphasize paying attention to emotion when giving bad news could be adapted for neonatology and obstetrics, to improve communication between physicians and families facing decisions regarding resuscitation.^{31–34}

All subjects in this study recalled wanting to participate in decision-making. Most had discussed anticipated complications for the pregnancy and the infant with multiple physicians, but few could recall discussing resuscitation options. This was sometimes in contrast to physicians’ medical chart documentation. Undoubtedly, the retrospective nature of the interviews affected parents’ recall, although there were no significant differences in recall between parents who had lost their newborn <1 year versus >1 year before the interview. The emotional trauma of the experience likely affected all parents’ ability to understand and to remember all that occurred. There are other putative explanations for the discrepancy between parents’ recall and physicians’ documentation. Parents in this study described conversa-

tions with physicians as confusing, particularly when physicians used euphemisms to convey the gravity and urgency of the situation. Other authors have described physicians' use of euphemisms for "dying" and "death" as an unwitting form of "collusion," whereby physicians attempt to protect patients and themselves from bad news. Inadvertently, this deprives patients of adequate time to prepare for reality.³⁵ Physicians may think, and document, that they discussed resuscitation options with parents, but parents may leave the conversation with a different understanding. A recent study showed that physicians who discuss end-of-life decision-making assess the family's understanding of the decisions only 25% of the time.³⁶ Methods to improve patient-physician communication during prenatal counseling, including enhanced physician training in delivering bad news, could improve family members' understanding of medical information and increase parents' ability to participate in decision-making.^{31-34,37,38}

It is notable that few parents recalled discussing compassionate care. Again, it is possible that the subject was too disturbing for some parents to remember fully. It is also possible that physicians did not present all of the options. Martinez et al¹³ reported that physicians' behavior was highly variable when they were counseling families regarding life-sustaining therapies for extremely preterm infants, with 10% to 80% regularly discussing compassionate care or withdrawal of therapies. Although time pressures, unanticipated medical emergencies, and lack of an established physician-patient relationship are well-described barriers, physicians may not offer the full range of resuscitation options to parents because of moral, religious, ethical, or legal concerns as well.^{4,39-41} A recent report suggested that nearly 30% of physicians neither discuss nor refer patients for procedures that the physicians themselves find morally controversial.⁴²

A distinct utility of qualitative methods is the hypothesis generation produced by unanticipated subject responses. An interesting finding in our study is that white parents were less likely than black parents or other minority parents to recall discussing compassionate care with physicians. Although the numbers were small, the finding was robust. Attitudes toward death and life-saving technology have been found to vary with race and ethnicity in other areas of medicine and are thought to result from a complex interaction of factors, including access to medical care, communication styles, family involvement in decision-making, trust in physicians, and religion.⁴³⁻⁴⁵ Although the adult literature has shown that black individuals are less likely than white individuals to have an advance directive and are more likely to desire all life-sustaining therapies, the relationship of race and ethnicity to decision-making regarding delivery room resuscitation has not been well defined.⁴⁶⁻⁴⁹ The findings of our small study are inconclusive but suggest that there may be an impact of race and ethnicity on discussions regarding high-risk pregnancies. Whether black parents had better recall of these discussions because they found them offensive, physicians offered

more-aggressive care to white parents, or other factors played a role should be explored in confirmatory studies.

There are several limitations to this study. The representativeness of our sample is difficult to assess, because of the limitations of the opt-in recruitment strategy. The sample size was small for subgroup analyses; larger studies are needed to confirm and to expand our findings. The interviews were subject to parental recall, and medical charts were used as a proxy for physicians' perceptions of communication with the family. Medical charts are notoriously incomplete, although the records in this study generally did contain documentation of decisions regarding delivery room resuscitation. Other authors have demonstrated that patient/provider recall immediately after prenatal counseling yields disparate accounts of which decisions were considered and made; a prospective study to record conversations would be needed to provide a more precise account.⁵⁰ No parent wished to be interviewed face to face, but additional information might be gained through face-to-face interviews.

Only parents of infants who died were interviewed, because descriptions of their experiences were limited in most existing studies of decision-making for critically ill infants. Parents with high-risk pregnancies that resulted in survival of the infant, with or without disability, might have had different experiences with physicians. All of our subjects were mothers; although several subjects did refer to their husband's or partner's participation in decision-making, fathers' values were incompletely explored. Although Spanish-speaking subjects were recruited to participate in this study, none was able to be enrolled. The issues unique to decision-making for these parents have not been described.

CONCLUSIONS

The values that parents in this study applied to decision-making regarding delivery room resuscitation, including religion, spirituality, and hope, are not routinely incorporated by physicians. This discordance in communication may contribute to confusion about what has been discussed and how decisions have been made. Future studies should explore methods to incorporate parents' values quickly and effectively into discussions of resuscitation, particularly in situations where established physician-patient relationships do not exist. Prospective methods should be used to examine the impact of prenatal decision-making on long-term family outcomes. The role of race and ethnicity in decision-making deserves exploration.

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EVIDENCE FOR THE IMPACT OF QUALITY IMPROVEMENT COLLABORATIVES: SYSTEMATIC REVIEW

ABSTRACT

Objective: To evaluate the effectiveness of quality improvement collaboratives in improving the quality of care.

Data sources: Relevant studies through Medline, Embase, PsycINFO, CINAHL, and Cochrane databases.

Study selection: Two reviewers independently extracted data on topics, participants, setting, study design, and outcomes.

Data synthesis: Of 1104 articles identified, 72 were included in the study. Twelve reports representing nine studies (including two randomised controlled trials) used a controlled design to measure the effects of the quality improvement collaborative intervention on care processes or outcomes of care. Systematic review of these nine studies showed moderate positive results. Seven studies (including one randomised controlled trial) reported an effect on some of the selected outcome measures. Two studies (including one randomised controlled trial) did not show any significant effect.

Conclusions: The evidence underlying quality improvement collaboratives is positive but limited and the effects cannot be predicted with great certainty. Considering that quality improvement collaboratives seem to play a key part in current strategies focused on accelerating improvement, but may have only modest effects on outcomes at best, further knowledge of the basic components effectiveness, cost-effectiveness, and success factors is crucial to determine the value of quality improvement collaboratives."

Schouten LMT, et al. www.bmjonline.com. June 24, 2008

Noted by JFL, MD

Values Parents Apply to Decision-Making Regarding Delivery Room Resuscitation for High-Risk Newborns

Renee D. Boss, Nancy Hutton, Leslie J. Sulpar, Anna M. West and Pamela K. Donohue

Pediatrics 2008;122;583

DOI: 10.1542/peds.2007-1972

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