
REVIEW

Review on Neonatal End-of-life Decision-making: Medical Authority or Parental Autonomy?

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ABSTRACT

As advances in medical technology are constantly re-defining the lower limit of newborn viability, the practice of withholding/withdrawing treatment in neonatal care is increasingly prevalent. Now more than ever, physicians working in neonatal intensive care units have to constantly face the ethical dilemma of terminating the neonates' life support, sometimes against the parents' desire. Traditionally and legally, parents have the duty to make decisions on behalf of their infants because they are the ones to whom the consequences matter the most. Physicians, on the other hand, often claim for themselves the role of the child's advocate, with the growing acceptance of the patient's "best interest" standard as the guiding principle. In this mini literature review, the authors examined the issue of medical authority versus parental autonomy in neonatal end-of-life (EoL) decision-making and found that consultations with parents were made in the majority (79-100%) of cases. Furthermore, conflicts between doctors and family were shown to occur quite frequently due to barriers to effective communication such as strong religious convictions and disagreements within medical team members. Only by encouraging active parental participation and overcoming some of these barriers, physicians and the patient's family could arrive at an ethically sound EoL decision.

Keywords: Autonomy, Medical ethics, Neonates, Paternalism

INTRODUCTION

In 1990, baby Sidney Miller was born at 23 weeks via emergent oxytocin induction due to maternal chorioamnionitis. Just prior to delivery, her parents had expressed to the obstetricians and neonatologists their wishes for no "extraordinary, heroic" measures because of the child's extreme prematurity. Nonetheless, all parties agreed that the child, if born alive and vigorous, should be resuscitated. Within the next few weeks at the Houston Neonatal Intensive Care Unit (NICU), the neonatologists, with parental consent, gave her vitamin E, surfactant, blood transfusion, inserted a central line, and subsequently a cerebroventricular shunt after baby Miller developed Grade III/IV intraventricular haemorrhage. At the age of 14, Sidney Miller had undergone numerous surgeries to repair the shunt and sustained severe mental and physical disabilities — she was blind, unresponsive and completely paralysed. Her parents sued the hospital for providing life-sustaining treatment

despite their earlier wishes and were awarded US\$30 million for actual medical damages.

The Miller versus Hospital Corporation of America (HCA) controversy exemplifies the ethical dilemma of withholding/withdrawing treatment as well as the tension between physicians and the patient's family in deciding end-of-life (EoL) issues. Traditionally and legally, parents have the duty to make decisions on behalf of their infants because they are the ones to whom the consequences matter the most. Physicians, on the other hand, often claim for themselves the role of the child's advocate, with the growing acceptance of the patient's "best interest" standard as the guiding principle. In this mini-review, the authors aimed to explore the tension between medical authority and parental autonomy when making neonatal EoL decisions. In particular, the authors studied how and why clinician-family conflicts could arise, and identified some of the common barriers faced by

many clinicians in this decision-making process.

METHODS

To explore parents' and healthcare professionals' involvement and their communication in end-of-life decision-making in the neonatal intensive care units, I performed a literature review using the MEDLINE, EMBASE and CINAHL databases. With the following keywords: neonatal intensive care, end-of-life, ethical or medical decision-making, parents, parental attitudes, informed consent limited by English and by publication year from 2000 onwards, 72 pertinent results were identified. Citation-index and ancestry searching yielded 12 more publications. Studies in which measurable outcomes are not immediately relevant to our understanding of physician-and-family communication and their attitudes were excluded. Several studies (including the large-scale EURONIC survey to investigate doctors' self-reported practices of withholding and withdrawing treatment in 11 European countries¹⁻⁴) were identified to document only the physicians' involvement in making the EoL decisions and were therefore excluded. Review articles, case reports and articles relating parents' experiences in the decision-making process were also not included in the analysis due to the lack of primary research data⁵⁻¹¹.

RESULTS

Eight studies were included in the final analysis of the decision-making roles and communication between healthcare professionals and family in the neonatal intensive care environment and its perceived effect on ethical decision-making. The studies were conducted in various European countries including UK, the Netherlands and Belgium, countries of the Pacific Rim and Canada. The studies' design, methods and outcomes are summarised in Table 1.

DISCUSSION

Should Parents Be Involved in the End-of-life Decision?

Neonates, unlike adults, cannot decide for themselves, make a living will, or express their opinions on issues such as quality of life. Nor have they any previous life experiences that the surrogate decision-maker can draw upon in order to decide in the infant's "best interest". Physicians have traditionally assumed the role of the infant's advocate, although many believe that parents should be involved in decisions as they have to live

with the consequences. The American Academy of Pediatrics (AAP) Guidelines in 2007 stated that "for infants with poor prognosis, decisions about treatment should be made jointly by the healthcare team and the infant's family" and that "parents should be active participants in the decision-making process"²¹. The Singapore Ministry of Health's "Ethical Guidelines on Medical Treatment of High-risk Infants" in 1997 echoed this viewpoint — "parents should be actively involved in major decisions that ultimately could alter the infant's outcome. The parents bear the principal moral responsibility for the well-being of their infant and should therefore be the surrogates for their infants"²².

A survey from parents of seven countries or cities of the Pacific Rim found that joint decision-making was strongly preferred over decisions made by physicians or parents alone. In another study, when asked "Who should make the final decision?", the overwhelming majority (90-100%) of both doctors and parents felt that the family should have the final word¹⁶. In this same study, 99% of physicians believed that they, too, should decide; while only 72% of parents agreed.

Despite this prevailing attitude, discussion between medical professionals and the family was found to be quite variable. The studies showed that consultations with parents were made in 79% to 100% of cases before an EoL decision. Provoost et al identified 22 of 136 deaths in which the parents were not consulted, due to reasons such as the lack of time, the physicians' belief that "the situation was so obvious... there was no reason to consult the parents", or the parents' stated wish to hasten the end-of-life during therapy¹⁸.

Who Decides for the Neonate's End-of-life?

Only two studies adequately examined the parents' perception regarding who made the decision for their infants' death (Table 2). JC Partridge et al found that in seven Pacific Rim countries, only a minority (0-5%) of parents felt that they alone had made the decision¹⁶. Joint decision-making was reported to be the prevailing procedure in most places, except Melbourne where 74% of parents perceived that the physicians had decided alone¹⁶. In contrast, according to the study done by McHaffie et al, 42% of parents described that they alone had made the decision, and only 14% felt the decision was jointly made^{12,13}.

Table 1. Summary of Research Studies (in chronological order) used in this Review.

Study, Year	Country	Sample	Design	Methods	Measured outcomes
HE McHaffie et al, 2001 ^{12, 13}	UK	176 doctors and nurses in 6 NICUs; 108 parents of 62 babies	Qualitative descriptive	In-depth, face-to-face audiotaped interviews were conducted in a semi-structured schedule focusing on the policies and practices, factors influencing decision-making, and the involvement of parents.	The nature of the decision-making process; who does decide; different perceptions between doctors and parents.
DL Streiner et al, 2001 ¹⁴	Canada	98 neonatologists and 99 neonatal nurses in 3 tertiary care units; 169 parents of ELBW children and 123 parents of term children	Quantitative survey	Self-reported anonymous questionnaires were completed by parents and health care professionals in private settings.	Perceptions of the risk of disability in ELBW infants; attitudes toward active treatment and who should be involved in the decision-making
R Roy et al, 2004 ¹⁵	UK	71 infants in 1 tertiary neonatal care unit.	Retrospective study	Case notes of infants who died by withholding or withdrawing of life-sustaining treatment, do-not-resuscitate orders and natural means were reviewed.	Mode of death and characteristics of the deceased newborns, parents' agreement or refusal of withdrawing life-sustaining treatment.
JC Partridge et al, 2005 ¹⁶	Taiwan, Hong Kong, Singapore, Kuala Lumpur, Tokyo, Melbourne, San Francisco	327 parents of 379 VLBW infants in 9 NICUs in 6 Pacific Rim countries and 2 California hospitals.	Qualitative descriptive	Half-hour, face-to-face interviews or by telephones using an "interview tool" (an abbreviated questionnaire) translated into Chinese, Malay and Japanese.	Parents' perceptions about effectiveness of physicians' counseling during their infants' care; parents' attitudes on the optimal locus of decision-making between physicians and parents; parents' satisfaction and suggestions for improving overall NICU care.
AM Vraking et al, 2005 ¹⁷	The Netherlands	299 physicians involved in 184 EoL decisions in 1995; and 233 physicians involved in 154 EoL decisions in 2001.	Quantitative survey	Four-page self-reported questionnaires focusing on the decision-making process and whether death had been hastened by decision to forgo life-sustaining treatment or by the use of life-shortening drugs.	Characteristics of EoL decisions for children aged younger than 1 year: place of death, diagnosis, reason of decision, use of drugs with possible life-shortening effect, discussion with parents and others.
V Provoost et al, 2006 ¹⁸	Belgium	253 physicians attending to EoL decisions regarding 298 infants' deaths.	Quantitative survey	Anonymous questionnaires aimed at identifying different types of EoL decisions were mailed and collected from the participants.	Consultation with parents; physicians' withholding and withdrawing potentially life-prolonging treatment; alleviation of pain and/or symptoms with drugs with a potential life-shortening effect; the administration of lethal doses of drugs.
AA Eduard Verhagen et al, 2007 ¹⁹	The Netherlands	All neonatologists involved in EoL decisions in 30 infants' deaths at 2 tertiary NICUs	Retrospective study	Case notes of infants who died with or without a medical EoL decision were reviewed; the responsible neonatologists were interviewed.	Patient characteristics and diagnoses leading to EoL decision; parental consent and team decision; use of potentially life-shortening medications.
AA Eduard Verhagen et al, 2009 ²⁰	The Netherlands	All neonatologists involved in EoL decisions of 147 infants' deaths at 10 tertiary NICUs	Retrospective study	Case notes of infants whose deaths were preceded by an EoL decision were reviewed; the responsible neonatologists were interviewed.	Parents' involvement; conflicts between members of the medical team and between parents and medical team; characteristics of the cases that involved those conflicts; risk factors for conflicts.

Table 2. Who Makes the Decision^a?

Physicians alone	Joint decision-making	Parents alone	Study
44%	14%	42%	HE McHaffie et al ^{12, 13}
12-20% in four cities ^b including Singapore	75-86%	0-5% in all cities surveyed ^c	JC Partridge et al ¹⁶

^a Data are based on parents' perception of who decided the neonates' end-of-life treatment.

^b Hong Kong, Singapore, Kuala Lumpur, San Francisco. ^c Cities surveyed also include Tokyo and Melbourne.

The findings in these two studies differ widely, possibly because they recorded the parents' subjective assessment of the decision-making process. McHaffie et al suggested that many parents might have identified themselves as playing the final decisive role since they were not aware of any prior team discussion^{12,13}. Often, the medical team has already obtained a sense of the preferred medical decision before a discussion with the parents takes place. Regardless of the underlying cause, these data showed that the extent to which parents are comfortable with taking a primary role in medical decision-making can be quite variable. While some parents are willing to bear the responsibility, others prefer to act according to doctors' advice. The role of the physicians, therefore, is to actively assess how dominant a role they wish to assume in their child's treatment decisions. In trying to understand the parents' preferences, the physicians could also heighten their trust, enhance their comfort level in reaching life-and-death decisions and ameliorate their subsequent guilt and grief.

Barriers to Effective Communication

Many barriers to good communication have been reported by both clinicians and the infant's parents regarding the decision-making process

(Table 3). AA Eduard Verhagen et al identified religious conviction as the strongest parent-related risk factor for conflict, followed by difference in cultural background and educational level²⁰. Poor communication and conflict within the medical team were the strongest team-related risk factors. As far as possible, physicians therefore should strive to improve their communication skills and prevent internal conflicts from interfering with diligent patients' care.

Many physicians felt that having parents involved in decision-making was too time consuming. They believed that parents might find it hard to cope with these tragic decisions and often needed more time to accept reality¹⁸. Time constraint, however, should by no means compromise the physicians' duty to engage the parents in a thorough dialogue, especially when crucial decisions about their children's EoL care need to be made. Some doctors also considered the decision to withdraw life-sustaining treatment too heavy a burden for the parents to bear¹³. Another cause for anxiety among many physicians is the potential burden of guilt they may create for the child's caregivers¹². A study done by McHaffie et al, however, showed that these various concerns may not be completely

Table 3. Barriers to Effective Communication between Physicians and Family.¹²⁻²⁰

Physician-related factors	Family-related factors
Poor communication with parents	Strong religious conviction
Conflict within the medical team	Different cultural background
False perception of parents' ability to bear decision-making role	Low educational level
Decision-making too quick for parents	Poor communication skills
Decision-making at an inappropriate time for parents	Language problems
Failure to disclose all the information or to present the information in an understandable way	Negative previous medical experiences
Lack of humility or compassion	Disagreement between parents
Many different attending physicians per infant	
Little request for parental opinion	
Strong religious conviction	

well-founded. The majority of parents surveyed thought that the decision-making role was part of their natural responsibility — of 60 parents who believed they had made the final verdict, only one person felt that the decision was burdensome although it was nonetheless theoretically right¹².

Inappropriate timing of discussion was also a significant barrier for effective communication. The American Academy of Pediatrics guidelines advised that “whenever possible, discussion between the physician and parents should begin before the birth of a child with anticipated poor prognosis”²¹. Nonetheless, McHaffie et al showed that the first mention of treatment limitation only took place antenatally for only three of 59 (5%) families^{12,13}. The majority of parents (63%) were first informed within postnatal day one to seven, and three (5%) parents were actually informed during labour. It is quite likely that communication regarding EoL decisions brought up at a time of such emotional vulnerability will be ineffective. In fact, in a descriptive study by Brinchmann et al, many parents felt that they were not capable of making rational decisions when in shock or crisis²³. Furthermore according to Tripp and McGregor, parents often perceived that the physicians’ advice to withdraw active medical care came as a complete surprise or “bolt out of the blue” after their prognostic enquiries have been met with positive outlooks²⁴.

Conflicts Between Physicians and Family

Three studies focusing on physician-parent conflicts showed that they did occur rather frequently in the NICU practice (Table 4). The majority of these conflicts arise from the parents’ refusal to withdraw life-sustaining treatment despite the medical team’s suggestion to do so, given the infants’ poor diagnoses or prognoses. As clinicians, it is important to remember that the parents’ rights should always be respected for they bear the moral and legal responsibilities for their children. At the same time, the Singapore Ministry of Health stated that doctors “should not be forced to under-treat or over-treat an infant if, in their best medical judgement, the treatment is not in compliance with the standards of care”²².

Changing the aim of therapy from curative to palliative is a highly emotional decision that often comes gradually as the infant’s clinical condition deteriorates. During their collaborative relationship, physicians should take opportunities

Table 4. How Frequent does Conflict Arise?

Frequency	Study
11/39 (28%)	R Roy et al ¹⁵
4/114 (3%)	V Provoost et al ¹⁸
18/147 (12%)	AA Eduard Verhagen et al ^{19,20}

to explore the parents’ underlying reasons for differing judgement, and ensure that medical facts are clearly understood. Multiple discussions with the parents, with possible involvement of other medical experts or an interdisciplinary team, may help parents and physicians reach a consensus. Finally, the hospital ethics committee could be consulted, but only as the last resort.

CONCLUSION

As advances in medical technology are constantly re-defining the lower limit of viability, the practice of withholding/withdrawing treatment in neonatal care is increasingly prevalent. Over three decades ago, Duff and Campbell first described the presence of EoL decision-making prior to 14% of deaths in a special care nursery²⁵. Today, such decisions have been reported with frequencies as high as 74%²⁶. Now more than ever, physicians working in neonatal intensive care have to constantly face the ethical and moral dilemma of terminating their patients’ life support, often against the family’s desires. In this mini-review, I sought to examine the nature of physician-parent conflicts, as reported in eight relevant primary studies around the world. I have found that these conflicts could arise from the physicians’ failure to adequately involve the child’s family in the decision-making process. However, while many physicians may feel that making life-and-death decisions may cause too great a burden for the family, the majority of parents actually recognise this as their inherent duty. Furthermore, many national guidelines, including that in Singapore, clearly advise medical professionals to include the family in EoL discussions. Thus the physicians’ role is to assess how actively involved the parents wish to be and engage them accordingly.

Given the contentious and difficult nature of EoL decisions in neonates, it is not surprising that physicians and parents may sometimes find themselves in a tug-of-war, due to the parents’ strong religious background, the medical team’s poor communication or simply bad timing. More often than not, conflicts resolve over time as the neonates’ condition alters. As physicians, however,

it is important to recognise and tackle problems within the medical team that could contribute to this tension, especially those that are preventable. Some examples include language barriers, internal disagreement about treatment options, and inappropriate time to inform about withdrawal of care.

Finally, it is also worth noting that all those involved, doctors and parents alike, could themselves harbour beliefs and preconceptions that may not contribute to the best interest of a sick baby. Only through an honest collaborative relationship can physicians and family learn from each other's values and make a final decision that they can mutually agree on.

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