Editorial

THE INTERNATIONAL SECTION: FROM THE EDITOR

Several years ago, the editorial board of the Journal of Perinatology decided that it would be interesting to our readers to learn how perinatal/neonatal care was practiced all over the world. It was our belief that by sharing past history and current techniques and advances there would be an improvement in the total spectrum of maternal/newborn care. Under the guidance of Dr. Dharmapuri Vidysagar and Dr. Arthur Eidelman, this project has been completed. Starting with this issue (pages 528–532) material will be presented from the Middle East, Asia, Latin America, and Europe. The historial value of such an indertaking is priceless. The possibility of decreasing mortality and morbidity from sharing this information is real. We hope you enjoy this section of the Journal *and await your comments.*

—Gilbert I. Martin, MD
Editor-in-Chief

Communication Gap

Gilbert I. Martin, MD

Tuesday morning, 11 AM; just finished making rounds on a 13-day-old SW, a 650-gm infant of 24 weeks' gestation who was still on high-frequency ventilation. The baby just finished a second course of indomethacin, and the ductus remained opened. His parents will be disappointed, I thought, as surgery would now have to be discussed again. "Don't forget to call Mrs. W," whispered Sherri Alexander, Sam's nurse. "No one spoke with her yesterday" she chided. "Fine," I answered, "please get her on the phone." "Am I his slave too" thought Sherri, as she dialed the number. The phone rang six times without an answer. There was no answering machine. "No one home," Sherri said as she hung up the receiver. "Okay, okay. I will call her back later," I said. But, I knew that this would probably not happen. On call, with six more patients to see; where would I find the time? Communication with parents, so important . . . but.

Sound familiar? It should. Elsewhere in this issue (p. 525), Nancy Montalvo and Brian Vila recount their neonatal intensive care unit experience in great detail and with great frustration and anger. Repetitive words and phrases such as choices, contradictory information, distrust, questioning, and ethics appear frequently throughout their commentary. Although experience teaches us that parents and families often have selective hearing, and focus on the good news while avoiding the bad until a crisis occurs, many of their comments are valid and should make all members of the nursery staff step back and reflect.

At first welcomed into the neonatal intensive care unit, their questions became more probing and made the physicians feel uncomfortable. Soon, they felt punished and believed that they were victims of a "medical assault." The life of this family has changed forever, and they believe that "neonatologists who bring these burdens into another life without permission should be held accountable."

Have we as physicians and nurses taken an aggressive rescue policy to the extreme? New technologies develop a life of their own, and as Peabody has stated "just because we can, is it the right thing to do?[1] The debate continues, spurned on by the Baby Doe regulations and the right-to-life rules. Physicians now make value judgements, while at the same time considering the medical-legal implications of their actions. Are parents really given complete "informed consent?" Do they understand all the consequences of a therapy or procedure? It is not practical or is often impossible to discuss all of the risks/benefits of a specific medication or therapy. If a "misadventure" occurs, parents feel that they have been overlooked. Neonatology is without simple cookbook recipes, and even guidelines need to have disclaimers.

There are ethical and economic issues that are raised together but are not easily separated. Do we really "listen" enough to parents? We look forward to telephone consents, for they are easier to get and are quicker. We overload babies with harsh external sound and light and oftentimes do not consider the consequences. Parents are becoming more involved in the care of their infants and in some institutions make rounds with the neonatal team. Family centered neonatal intensive care unit care and a kinder, gentler approach to the infant and family are the new buzzwords.

However, the most important word still remains "communication." Despite a well-intentioned approach, we rarely communicate enough with parents, especially when their availability is not convenient. I wish I knew the answer. Scheduled family conferences and mandatory daily telephone calls may help, but this is still not enough. As healthcare providers, we all have personal beliefs, both intellectual and religious, that are not always objective. I believe that parents need to be part of the decision-making process and need to know that there

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are choices. In my experience however, most parents want "everything done" even when advised that there is grim prognosis for a meaningful life.

Setting limits on viability has not been successful. Anecdotal stories abound about a former 450-gm infant who is now entering college on scholarship. Physicians are pressured daily about cost and that ALOS (average length of stay) term. Can we ration care? If so, who decides? Randomized clinical trials and evidence-based medical information offer some hope, but we know that neonatal intensive care unit care is often plagued with "therapeutic exuberance."

This editorial raises more questions than answers. So did the commentary by Nancy Montalvo and Brian Vila. Take a moment to think about this; we welcome your comments.

References

1. Peabody J, Martin G. From how small is too small to how much is too much: ethical issues at the limits of neonatal viability. Clin Perinatol 1996;23:473–89.