

Burdens Beyond Biology for Sick Newborn Infants and Their Families



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KEYWORDS

- Infant • Newborn • Costs and cost analysis

KEY POINTS

- Outcomes in neonatology have focused mainly on the biological outcomes of the babies under our care, resulting in a “proband” and a “biological” bias in the literature.
- A “slower medicine” in the NICU would recognize the distinction between the remarkable technical capabilities of the modern medical world and how those intersect with our society, and its values, more broadly.
- Considering outcomes such as impact on families, as well as other financial and other stressors, would not require foregoing effective therapy or the improvements in mortality and morbidity it has brought.

The following is a modified transcript of the 2017 Kristine Sandberg Knisely Lectureship, which was delivered at the Children’s Hospital of Philadelphia in May 2017. The Lectureship honors the memory of Kristine Sandberg Knisely, MD, a 1949 graduate of the University of Pennsylvania School of Medicine and The Children’s Hospital of Philadelphia residency program, who became a neonatologist and Associate Professor of Pediatrics at the same institutions, and made significant contributions in public health initiatives and research involving newborns.

We are rightly proud of what we have accomplished in neonatology. According to traditional benchmarks, outcomes for sick newborn infants have never been better. Horbar and his colleagues¹ examined the outcomes of 408,000 very low birth weight infants at 756 centers in the Vermont Oxford Network, in 2005 and in 2014. They found that, in 2014, almost 100% of neonatal intensive care units (NICUs) reported mortality that was as good as the top 10% of units in 2005. There were similarly large

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improvements in late-onset infection, necrotizing enterocolitis, severe intraventricular hemorrhage, and severe retinopathy of prematurity. Of course, absolute numbers of infants with these conditions remain high, but we can say unequivocally that, at the unit level, we are all being pulled up by a rising tide, and an infant is less likely to have these conditions now than a decade ago.

We have also long known that that is not the whole story. In part because the biological outcomes at borderline viability were poor, and in part because the cost, not just in financial terms but also human terms, such as time in the NICU, was high, neonatologists started examining outcomes that went beyond neurodevelopmental impairment rates, acute morbidity, and mortality. One of the earliest innovators in this arena was Saroj Saigal, who began to measure functional health outcomes, and to use these to quantify quality of life, using tools originally developed in economics.

Saigal assessed children in a geographically defined cohort of 141 extremely low birthweight (ELBW) adolescent survivors born between 1977 and 1982, and 124 term controls.² Instead of just cataloging rates of impairments, she collected measurements of functional health status, which included measures of the traditional sensory, mobility, and cognitive domains, but also emotion, self-care, and pain. Within each of those domains, there were 3 to 5 levels of increasing functional impairment. The domain of emotion, for example, might be anchored on 1, describing someone who is generally happy and free of worry, to 5, describing someone with extreme symptoms requiring high levels of psychiatric intervention. When comparing her ELBW patients with controls, functional health status differed between ELBW adolescents and controls in all domains. The really innovative contribution, though, was in measuring children's preferences for living in the state they were in. This involved assigning a value between 1 (for perfect health) and 0 (for death), using a process that is well-described in decision theory, called a standard gamble. Essentially, this was a subjective rating of how satisfied the children were with their overall health, including all the domains in the health status measure. It is a numerical estimate of quality of life, or conversely of "suffering." As expected, ELBW adolescents reported lower quality of life than the term adolescents, driven by a combination of the various domains. This finding continued into later life, as quality of life decreased steadily over time.³ Importantly, while baseline rates were lowest among infants with neurosensory impairment (that is, cerebral palsy, blindness, deafness, or microcephaly at 3 years), they were still significantly different in adults without neurosensory impairment. There is thus a quality of life burden here that is not related to our traditional biological measures. What underlies these quality of life decrements?

A clue may lie in the fact that, in that same cohort, even those ex-preterm adults who did not meet the definition for neurosensory impairment had some indicators of underlying medical conditions, such as mental illness, learning disabilities, subtler motor problems such as self-reported clumsiness, or mild visual deficits. In other studies, these would typically not be enough to drive down numerical quality of life indicators to the levels observed. But importantly, the graduates also were less likely to work full-time, had substantially lower income, were more likely to receive social assistance, and were less likely to date or to be married. Whether these outcomes were secondary to biological deficits is not known.

These studies have really just started to tilt our perspective away from its traditional biological bias to a more holistic view of patient outcomes. Importantly, the work also applies to infants born in an era during which care in the NICU was very different. Just as is the case for neurodevelopmental impairment, though, that caveat is balanced by the fact that today's borderline viability is also much more biologically tenuous. The lesson is that measurement of pulmonary function tests, hypertension, even

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