Partial Survivors: The Brokenness of Intact Survival

Paul C. Mann

ABSTRACT

Intact survival is a medical phrase that denotes a patient's survival following critical care hospitalization that does not include residual neurologic impairments. First proposed as the ideal neurodevelopmental outcome for prematurely born infants in the late 1950s, it remains a commonly cited neurologic outcome goal in the medical literature for patients of all ages. A clinical focus on intact survival, however, may have unintended consequences when neurologic outcomes are uncertain, contributing to a fallacious understanding of neurodevelopmental impairments and detrimentally impacting families whose children suffer neurologic disability.

William A. Silverman, MD, an influential and distinguished pioneer in the field of neonatology, left behind an enduring legacy at his death, with innumerable landmark contributions to medical science.[1] For these many notable accomplishments, however, one lasting influence Silverman has had on medical parlance and perspectives of neurologic outcome is infrequently, if at all, attributed to him.

In October of 1958, Silverman was honored by the Society for Pediatric Research with the E. Mead Johnson Award and invited to speak at the annual meeting of the American Academy of Pediatrics. His address focused principally upon research he had been conducting into the impacts of variable incubator settings on survival for infants who had been born prematurely.[2] The talk took a more philosophical turn towards the end, however, as Silverman pressed the importance of targeting a goal beyond survival in determining optimal environments to care for premature infants. His audience was asked to consider the substantive rates of brain injury in survivors of neonatal intensive care and to direct their efforts towards a more ideal clinical outcome that he coined "intact survival." While improving neurodevelopmental outcomes for premature infants was the implicit objective of this proposal, no specific targets were offered by Silverman by which to judge which infants survived their intensive care ordeal "intact." Silverman did disclose, however, his creative inspiration for these formative ideas about quality of survival was an entomological study outlining ideal incubator temperatures for rearing European brown-tail moths.[3]

The speech seems to have profoundly influenced the perinatal community. Within 10 years, the goal of intact survival had become so entrenched within its collective consciousness that it received substantial attention when multidisciplinary experts convened in 1969 at the National Institute of Child Health and Human Development to discuss key issues in infant mortality. The published report of that conference mentions Silverman's ideal of intact sur-

Paul C. Mann, MD, is an Associate Professor in the Department of Pediatrics, Division of Neonatology, Medical College of Georgia at Augusta. *pamann@augusta.edu*

vival more than 15 times.[4] Conference participants expressed their desire to shift the focus of neonatal medical care from a reduction in infant mortality towards ensuring that all survivors became "whole, healthy individuals." A good deal of difficulty, though, was confessed with defining what exactly constituted intact survival. "Do we use IQ levels? Motor development? Where do we draw the line between someone who will be a useful member of society and someone who will not?" wondered those participating.

These struggles were echoed in the 1972 *Report of the President's Committee on Mental Retardation,* which both championed and cautioned against embracing modern technology to save the lives of premature infants and high-risk infants born at full term.[5] The report noted that while a large percentage of babies treated with intensive care approaches may survive, many would "emerge with serious mental defects." Deeply concerned with such outcomes, one physician affirmed that, in caring for these babies, "the goal is not survival, it is intact survival."

The phrase intact survival remains prevalent throughout medical literature for neonates, children, and adults to help qualitatively label desirable and undesirable neurologic outcomes for emergency and critical care interventions. Descriptive characterizations of what it means to be neurologically "intact" vary greatly, though, if they are defined at all. Some studies describe intact survival as survival without serious morbidity[6] or survival with an absence of poor prognostic factors such as intraventricular hemorrhage.[7] Others studies denote intact survival as the avoiding specific sequelae like cerebral palsy and blindness[8] or maintaining the ability to carry out daily living activities independently.[9] In general, adolescent and adult patients survive life-threatening events such as traumatic brain injury or cardiac arrest "intact" if they regain their pre-state baseline without significant residual neurologic deficits.[10] For neonates and younger children, surviving hospitalization "intact" necessitates recovery from a critical illness without long-term neurodevelopmental impairments.[11]

The ongoing use of intact survival to describe the outcome of survival without neurologic disability, however, is problematic for patients of all ages. While the motivation for clinicians to use this terminology is probably multifactorial, fears of a poor future quality of life following neurologic injury are likely a central concern, with a desire to avoid burdening patients, caregivers, and society at large with significant neurologic disability as a clinical outcome. Quality of life concerns and the possibility of future neurodevelopmental impairments are commonly cited reasons for withdrawing life supportive care in children, especially neonates.[12] Quality of life estimations, though, are decidedly personal, value-laden, and subject to significant biases.[13] Troublingly, health professionals have been reported to have misinformed stereotypes and pejorative opinions of individuals with neurologic disability, including reduced valuations of their lives,[14] which could prejudice judgments of what constitutes an "intact" person.

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Evaluating neurologic injuries through the lens of intact survival may also encourage a fallacious binary paradigm in which a predicted neurodevelopmental outcome becomes a singular entity that the clinician judges to be either "good" or "bad." That is a harmful construct that is misleading for families, as it ignores the intricate complexity and fallibility of neurologic prognostication.[15] Following neurologic injury, children frequently develop variable degrees of long-term impairment in different, areas of neurodevelopment (for example, mobility may be much more impaired than cognitive functioning).[16] Neurodevelopmental outcomes for two patients with similar injury can be very different given the significant influences of a multitude of mitigating factors such as neuroplasticity and socioeconomic inequalities (for example, maternal education level, access to rehabilitative and special education services).[17] Some children will have outcomes that are much better than initially prognosti-

cated,[18] others much worse. To best aid clinical decision making in these contexts, especially as it relates to conversations regarding limitations of life-supportive care, families must comprehensively understand the distinctive types of possible functional impairments for their child and receive specific descriptions of how daily living may be altered. Parents can then discern for themselves how those potential outcomes might affect their family, defining "good" and "bad" on their own terms.[19]

It is imperative to critically appraise the ramifications of clinical concerns for intact survival and neurologic disability on patients' outcomes. The impacts of negative views of disability on medical decision making are understudied, but likely contribute to worrisome patterns of paternalism when patients' neurologic outcomes are uncertain. The many forms of such paternalism include: counseling (and sometimes pressuring) families to discontinue life-sustaining interventions early in hospitalizations that have been complicated by neurologic injuries, when spontaneous respiratory functioning is unlikely if the patient is extubated from mechanical ventilation (the so-called "window of opportunity"); incessantly communicating poor neurologic prognoses to families (the underlying supposition being they must not "get it" or otherwise would be in agreement with the medical team to stop "aggressive" interventions); presuming a family will be unable to accommodate neurologic disability in their loved one; and conflating functional neurologic impairments into deterministic socioeconomic outcomes with certain deleterious impacts such as social isolation, impoverishment, and marital collapse.[20]

Initial communication from clinicians regarding potential neurologic impairments for a child can have lasting consequences on how a family copes with disability. A study by Graungaard and Skov reports that parents expected clinicians to appreciate the emotional impact of their words in these contexts, and expected clinicians to empathetically communicate worrisome neurologic prognoses.[21] Instead, many parents disclosed a troublesome disconnect between themselves and their medical careproviders descriptive judgments of their child's potential—namely that clinicians define the child in terms of disability, instead of possibility.[22] These discordant perceptions can lead to families distrust the intentions of the medical team, adopting a defensive posture to "protect" their loved one.[23]

Disparaging judgments of neurologic outcomes also can have detrimental impacts on disabled survivors, precluding their wishes to be seen as the persons they once were.[24] Children recovering from neurologic injury describe being keenly aware of how others, including healthcare providers, redefine their quality of life, and that they have substantial difficulties adjusting to the attitudinal limitations placed on their future opportunities.[25] Notably, such negative attitudes about quality of life with a neurologic disability ignore the enriching aspects of disability that many survivors and families experience.[26]

Descriptions of neurologic disability in critical care survivors that focus principally upon which patients are likely to survive "intact" are of limited clinical value. Linking the inherent worth of patients to their neurologic attributes and cognitive capabilities ignores more relational aspects of their personhood and risks a wide range of undesirable clinical consequences, such as careproviders spending less time with their disabled patients and not advocating adequately for their rights.[27] It is imperative, instead, that we more compassionately discuss potential neurologic injuries for our patients in terms of specific impairments, counseling broadly enough to include the range of possible outcomes and patiently enough for families to process the implications.

On a hopeful note, there is evidence that the phrase intact survival is beginning to fall out of favor, especially with neonatologists.[28] Historically, however, abolishing controversial language as it relates to disability (for example, "defective," "mongoloid," "retarded"), has not significantly lessened the challenges that individuals and families of individuals with developmental disabilities face in obtaining equitable, quality healthcare.[29] New models of care are needed for families who choose to accommodate significant disability in their loved ones, focused on comprehensive support throughout the various transitions in the patients' neurodevelopment.[30] In that spirit, perhaps it is time for the pediatric community to champion a goal of a different type of intact survival, keeping families intact whose children have suffered neurologic injuries.

NOTES

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