

Born to Live

Part I: Micropreemies in the NICU

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Abstract: Two medical specialties have seen technological advances that have major impacts on society: assisted reproduction and neonatology. The former is responsible for a 400% increase in multiple pregnancies of three or more. Prematurity and severe birth complications have gone up proportionally. Micropreemies are born as early as 23 weeks of gestational age, weighing about 700 grams. Neonatology endeavors to keep these micropreemies alive with a rising rate of success.

For micropreemies, life from birth onwards is charged with continuous traumatic stress physically, emotionally, and psychologically. In the neonatal intensive care unit (NICU), the heroics of the medical staff are possible because of their dedication, modern technologies, and pharmaceuticals as described in the book **Baby ER** by Edward Humes. The preemies who do survive suffer endlessly through medical emergency procedures, surgeries, tests, transfusions, and toxic medications, etc. Especially the micropreemies, fed by gavage tubes inserted directly into their stomachs, hooked on ventilators, oxygen tubes, pumps, intravenous lines, sense pads, and other wires, go through near death experiences while in the NICU for months on end. Parents are not able to deal with extremely and very prematurely born children.

Beyond the visible and easily discernible disabilities such as seizures, cerebral palsy, organ damage, retinopathy, etc., studies are finally catching up in showing that developmental delays, motor, speech, cognitive, and behavioral problems show up later to varying degrees. Still missing in the literature are anecdotal testimonies from the micropreemies grown into maturity.

Zusammenfassung: *Geboren um zu leben: Teil I. Sehr kleine Frühgeborene auf der neonatologischen Intensivstation.* Zwei medizinische Spezialgebiete haben einen technologischen Fortschritt gemacht, der für die Gesellschaft eine größere Bedeutung hat: künstliche Befruchtung und Neonatologie. Die erstere ist für einen Anstieg der Mehrlingsschwangerschaften von drei oder mehr Kindern um 400% verantwortlich. Parallel gibt es einen

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Anstieg an Frühgeburtlichkeit und schweren Geburtskomplikationen. Sehr kleine Frühgeborene kommen schon in der 23. Woche zu Welt und wiegen um die 700 Gramm. Die Neonatologie macht es möglich, diese sehr kleinen Frühgeborenen mit wachsender Erfolgsrate am Leben zu halten.

Für diese sehr kleinen Frühgeborenen ist das Leben von Geburt an mit einem Kontinuum an traumatischem körperlichen, emotionalen und psychologischem Streß belastet. Auf der neonatologischen Intensivstation (NICU) sind Höchstleistungen der medizinischen Teams möglich Dank ihrer Hingabe, moderner Technologie und moderner Pharmazie, wie dies in dem Buch „Baby ER“ (emergency room) von Edward Humes beschrieben wird. Die frühgeborenen Kinder, die überleben, leiden endlos durch medizinische Notfallmaßnahmen, operative Eingriffe, Tests, Transfusionen, toxische Medikationen usw. Besonders die sehr kleinen Frühgeborenen, die durch direkt in den Magen gehende Schläuche künstlich ernährt werden, die an Ventilatoren hängen, an Sauerstoffschläuchen, intravenösen Schläuchen, Sensoren und anderen Verkabelungen gehen über Monate durch Nahtoderfahrungen ohne Ende, während sie auf der Frühgeborenenstation sind. Eltern können diese sehr früh geborenen Kinder noch nicht an sich nehmen.

Über die sichtbaren und leicht erkennbaren Schäden wie Krämpfe, cerebrale Anfälle, Organschäden, Augenschäden usw. erfassen wissenschaftliche Untersuchungen allmählich, dass Entwicklungsverzögerungen der Motorik, der Sprache, der Kognition und Verhaltensprobleme später in verschiedenem Ausmaß auftreten. Was in der Literatur immer noch fehlt, sind Fallberichte über die Entwicklung von sehr kleinen Frühgeborenen.

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Introduction

Let me open with three, seemingly, unrelated statements:

- Life is a continuum from conception onwards.
- The brain needs a world to respond to, (Johnson 1992).
- Memory and perception are inseparable, (Leon Cooper, quoted in Johnson 1992).

As each individual genome steers the structural and functional development of the embryo through the gestational period of pregnancy and onwards, science has become increasingly cognizant of the fact that genes are largely responsible for the basic framework of the organism and that the environment customizes the entity into the unique individual that emerges with birth. Some scientists and researchers have rid themselves of the dogma that life begins with birth in favor of the reality that life begins with conception from which time genes and environment play their particular roles in the continuum of development shaping gradually the physical, emotional, behavioral, and mental being each one of us becomes. That the environment does imprint its influences on the developing embryo and fetus is all too sadly true considering fetal alcohol syndrome (FAS), crack or ‘snow’ babies, and, in this paper’s context, preemies.

Recently, Edward Humes, a prize-winning special reporter, published **BabyER** (emergency room). Unless otherwise so noted, the quotes are taken from this book. According to Humes, one out of ten babies born in the United States is premature, (p. 12). In Germany, it is about 7% of all births, (Linder 1998a). Today,

the range of prematurity is between twenty-three weeks and several days before due date. Thanks to the increasingly sophisticated medical technologies, micro-preemies of twenty-three weeks, weighing less than one and a half pound (or about 700 grams), have a ten percent survival rate and twenty-six-plus-weekers a ninety percent chance to stay alive, (p. 19). That is to say, if proper care is available. Over 470,000, or ten percent of the annual birth rate, will not receive the needed neonatal intensive care because of the present economy and with today's health care philosophy of hospitals preferring to market luxurious birth suites without a neonatologist on duty at all, (Field 2000, p. 12 & 13).

Though prematurity can be due to many factors, including a psycho-emotional lability of the pregnant woman, as well as stress, (Linder 1998a, 1998b; Azar 1999; Irving 2000), the leading cause of micropreemies today is assisted reproductive science. In the U.S., the unregulated clinics using techniques such as freezing eggs and embryos, borrowing DNA, and chromosome transplantation, have caused an epidemic of fertility-induced multiple births (Lemonick 1997). Since 1980, the rate of twins born has gone up fifty percent; the increase in triplets and higher multiples is four hundred percent, (p. 77). Multiple births now make up one in three deliveries. 'Litters' of five and more are not a curiosity any more. Especially for older women, prematurity and severe birth complications have gone up proportionally.

Materials

"The Neonatal Intensive Care Unit (NICU) at Miller Children's Hospital, Southern California's Long Beach Memorial Medical Center, is one of the largest units in the United States, treating about eleven hundred babies per year." "There, eighty-one percent of the low birth-weight micropreemies survive compared to a national rate of sixty-seven percent" (p. 65). Upon birth, these tiny creatures are brought to room 288 where each preemie is attended to by "eight or more nurses, two respiratory therapists, an attending physician, a neonatal fellow, a medical resident," and a host of specialists needed to treat the specific complications, (p. 8). Apropos, in 1997, medical history was made when the first living septuplets were born under the care of a 66-member medical team, (McCormick 1997). Room 288 is rife with noise, especially from the equipment such as ventilators with various pumps and pistons, high-pitched electronic bells of cardiac monitors, chimes of the pulse oximeter sensors, conversations among personnel, crackling loudspeakers announcing emergency situations, metallic pounding at the scrub sinks, and so on. None of this cacophony, nor the lights and the high energy activity is good for the hypersensitive preemies. They need ear protectors to keep from being overwhelmed by their new environment or even deafened, (Bender 1988, p. 9). "These tiny babies can lose twenty percent of their body weight through evaporation as they lack subcutaneous fat." "Their skins hang loose and tear easily. They retain neither heat nor moisture." "Their nervous system and brains cannot handle the overload of our world," (p. 18) "No organ or system in their bodies works properly, not even after three weeks of surgery, antibiotics, transfusions, and round the clock one-on-one care." "Their circulatory system still flows the wrong way, sending too much blood to the lungs." "This back-flow is an illness only outside

the womb due to an extra vessel” – the ductus arteriosus – “that in normal fetuses withers away” while the foramen ovale, or opening between the two atria, closes as the full-term time nears or shortly after birth, (p. 19). “They are so immature, they lack the instincts to suck, swallow, cough, even to breathe.” “Yet, they kick, yawn, and wave their puny doll limbs, tugging ineffectively at the tangle of wires, hoses, sensor pads, and IV lines covering them,” (p. 19). When agitated, they just lose consciousness and forget to breathe, i.e., succumb to apnea.

“The effects of lengthy periods without respiration and heartbeat (ca. twelve minutes) may cause organ damage or death beginning with the brain and progressing to the heart, lungs, kidneys, and liver. If the child can be resuscitated, he may suffer from cerebral palsy, developmental delays, paralysis, blindness, seizures, and worse later in life. Possibilities turn into probabilities with each passing minute without adequate oxygen,” (p. 42). They often crash – a code blue or dying situation for the emergency staff. They are brought back from the brink with injected medications that can prove to be toxic, requiring more chemicals to counterbalance the toxicity. In 1997, an Alabama court awarded parents of nine newborns \$27 million. They were injected with toxic amounts of painkillers the effects of which showed up much later, such as speech and motor problems, cerebral palsy, and other disorders (Associated Press 1997).

Micropreemies especially need to stay in this environment for months until minimally they have caught up developmentally with what would have been their normal birth date. Fifty-six percent of premature infants require re-hospitalization in the first year of life, primarily due to pulmonary infections and other problems such as asthma, (Conference Report 2000). Long-term monitoring and assessment of development becomes mandatory to minimize, if possible, lasting behavioral and learning problems.

At least in the NICU there is no longer any misconception about the “abilities of even the micropreemies to sense pain and be overwhelmed by it to a greater degree than an adult does,” (Sjezer 2000, p. 89). This is in part because the infants have neither developed any defense mechanisms – they are not psychologically and emotionally armored as grown-ups are – nor have they the ability of anticipation. So much in the form of handling, treatment, medical adversities comes to them as a total surprise. For example, adults can prepare themselves for surgery, infants cannot. “It is common for preemies to be negatively conditioned against touch. Some react violently to the slightest stimulus. Touching the younger preemies is precarious. At the end of the sixth month of pregnancy, the nervous system is functioning and hypersensitive, easily overwhelmed by too much stimulation. A gentle stroke can be felt as so painful by a micropremie, it not only withdraws its foot but may howl in agony, sending its heart rate through the roof,” (p. 146). “Even the sound of a nurse tearing a foil packet or the smell of an alcohol-soaked swab can cause a fit. The reactions are strong: oxygen saturation level in the bloodstream plummets which brings on the flashing monitors and urgent alarms. The nurses have to back off from whatever they are doing or risk having the preemie asphyxiate itself out of pique and pain,” (p. 95). Thus while normal infants thrive on physical contact, tactile touch, hugging warmth, and human interaction, preemies may learn to associate touch with pain, agony, and possible death threats.

This is a bird's eye view of the world these babies' brains must respond to. No one knows or even has raised the question: what goes on in their soul, mind, or heart? No one really knows the intimate subjective effects on the psyche of a life lived from about a week to sometimes over a year in a NICU – in isolating incubators with noisy high-tech equipment and constantly changing disembodied voices for company. (A case history of multiple birth traumas may provide some insights into the subjective aspects of one particular experience preemies go through, namely death threats. To be discussed in **Born to Live: Part II**, (Ingalls, next issue).

Of course, everything is done humanly and in the medical technology's power to upgrade their surroundings and allow parents to help care for their children as soon as possible to give the infants some emotional sustenance, which raises another issue: the parents themselves.

Many parents hope for, if not expect, a perfect baby at the end of a normal pregnancy. Assurance comes from undergoing proper prenatal care, sonograms, for some amniocenteses, and other means. But, "with a multiple pregnancy," for example, "one of the fetuses can kick a hole in the fetal membrane or 'water bag' with a foot the size of a thumbnail bringing on premature labor" and possibly caesarian delivery, (p. 75). The mother is unprepared. All parents of micropreemies have no inkling of the roller coaster ride that lies ahead of them in the NICU and life thereafter. Their hopes are dashed and raised from moment to moment often for weeks if not months on end. They can't reconcile the image of the dream baby in their mind's eye with the reality of a micropreemie. Their personal, professional, and social lives are stretched to the limit. If they do adjust, some mothers bond with the NICU and silently pray to the machines not to fail their child or children. By the time they bring their outwardly looking healthy baby or babies home, internal damage may begin to show its effects within a week, a year, or much later. Psychologically, some parents can't readjust and continue to treat the child as if it were still in the NICU, overprotecting it and making it the star of the family in whom they have invested so much emotionally, psychologically, and financially. Often, the normal children in a family with a disabled newborn or child grow up as "shadow siblings" who are emotionally and psychologically neglected in favor of the so-called miracle baby, (Cronin 1995; Saigal 2000).

Micropreemies are not just million dollar miracle babies, perfectly fine when they go home. On the contrary, they face life-long problems some of which require immediate attention from occupational and special therapists, (APA 2000, pp. 208–209).

Before they can go home, some must overcome a "feeding aversion because they have been force-fed through a gavage tube that goes straight into their stomachs. Resisting nipple is a predictable reaction," (p. 206). "Most have missed out on practicing separation from the mother's biorhythms in the womb. They have never learned to swallow, breathe, and suck as coordinated activities. Such neural connections are not in place yet since breathing machines and feeding tubes did it for them. Their brains must be introduced to the world of feeding. "When the nipple is given, the baby is confused and may breathe instead of swallow. If he does the wrong thing in the wrong order, he gags, chokes, or holds his breath until his oxygen saturation falls and he turns blue. The next time, he'll refuse the bottle

because he learned that it may asphyxiate him, (da Silva 2000, p. 267). Seventy-four percent of children with feeding skills disorder have a primary neuromotor dysfunction. Special occupational therapists are employed by some NICUs to help babies with feeding aversion and other problems, such as “terrors of intubation, ventilation, surgery, incubation,” touch, noise, attachment, etc. (p. 208). “The very tests and procedures that keep these babies alive also have the unintended effect of putting them through hell. And the babies get mad, crash, or go into a death dive,” (p. 208). In other words, NICU life does teach these babies behaviors and establish emotional response patterns that require psycho-therapeutical follow up, specialized skills parents obviously lack. “Sadly,” Patricia Malmstrom of Twin Services in California says: “studies have shown that parental abuses of multiples are more likely than of singleton children – anywhere from 2.5 to nine times, (Adler 1997).

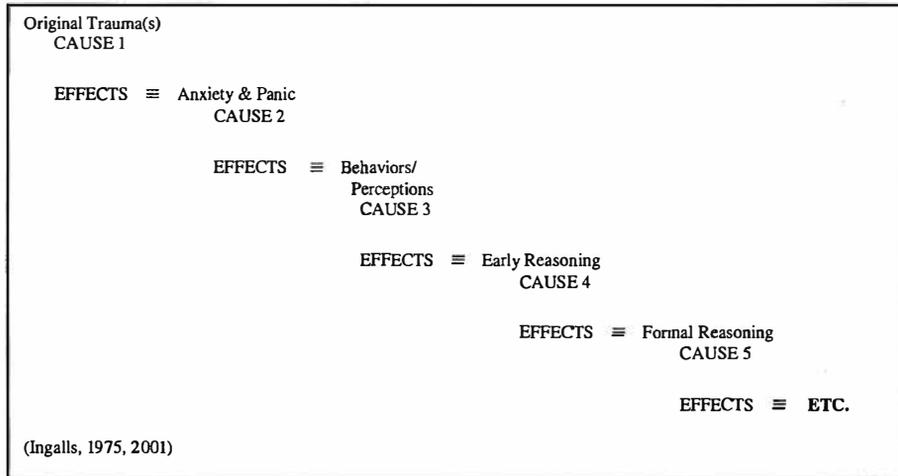
“Trauma is an experience.” “How is it,” asks Dr. Bruce Perry of Baylor College of Medicine in Houston, a leading expert in childhood trauma, “that such experiences can transform a child’s world into a terror-filled, confusing miasma that so dramatically alter a child’s trajectory into and throughout adult life?” “Ultimately it is the human brain that processes and internalizes traumatic (and therapeutic) experiences. It is the brain that mediates all physiological, emotional, behavioral, cognitive, and social functioning.” “In the developing brain, undifferentiated neural systems are critically dependent upon sets of environmental and micro-environmental cues to appropriately organize from their undifferentiated, immature forms.” During normal gestation, the period of greatest brain mass increase is from 24–28 weeks. “Lack (or disruption) of these critical cues can result in abnormal neural division, migration, differentiation, synaptogenesis – all of which contribute to mal-organization and compromised functions of the affected systems,” (Perry 1995). A case in question: “The stress and shock experienced by the premature infant after birth may cause periventricular capillaries to rupture. If the bleeding persists, it may lead to intraventricular hemorrhage. These ventricular areas are the sites for the formation and development of new brain cells that eventually migrate and form the outer layers of the cerebral cortex responsible for intelligence, learning, speech, behavior, and personality. It also influences muscle strength and control, (Simon 2000; Carter 1998). Research has shown that preemies are at a high risk for long-term learning difficulties, including cognitive and developmental deficits. One study found that certain brain areas involving the sensorimotor system and higher cognitive functions were considerably smaller in 8-year-old children who were born prematurely. The areas affected were the cortical subdivisions, ventricular system, cerebellum, basal ganglia, corpus callosum, amygdala, and hippocampus, (Peterson et al. 2000; Ajayi-Obe et al. 2000; Stewart et al. 1999).

For preemies, notably micropreemies, there is double jeopardy at work. First, their birth is from a protected, well-controlled, benign uterine environment into an highly stimulating and hostile one from which the infant cannot escape and where there is very little, if any, human comfort most normally born children receive. Second, they go through horrendous experiences and their senses are assaulted for which their developing brains are not prepared. Their skin, the largest sense organ, is prodded, pricked, injected, invaded with tubes, numbed and often surgically

knifed and sutured. Barring anesthesia, neurologically there is no defense against touch and handling, let alone massive pain. The neuronal imprints of numerous procedures and day-to-day life are indelible, leaving memories for life which are dissociated from consciousness and stored viscerally as anxiety and panic or as visual images of nightmares and flashbacks, (Marquez 2000; Brenner 2001). These first memories are not stored in the neocortex which still awaits development, but in the lower and midbrain, notably the limbic system which is partially mature at four weeks of gestation and fully formed by the third trimester of prenatal life which allows for pre- and perinatal somatic memory, (van der Kolk 1994). Also, the neurochemistry will be imbalanced. For example, prolonged stress causes the cortisol levels to be chronically elevated; overwhelming pain over a period of time can lower the dopamine production and inhibit dopamine receptor formation.

The lower brain is the site, among others, of reflexive and learned motor behaviors. The midbrain seats the emotions, relationship bonds, attachment behavior, self preservation, and stress related responses. According to Dr. Bessel van der Kolk, an expert on the effects of chronic trauma on development, “traumatized children store traumatic memories in the right half of the brain and the limbic system (midbrain) beyond the age of three. Normal people use both sides for positive and negative memories and at age three their higher level brain systems take over for memory functions. For traumatized children, the limbic system is constantly triggered by emotions and arousal, so other areas of the brain never develop to store and make sense of memory. They get caught up in their traumatic past which is the lens through which they view and respond to the present and current events.” In other words, memory and perception are inseparable. To them, life in the NICU is a standard by which new experiences are unconsciously measured unless countered by special care, therapy, and very understanding, patient parents. Traumatized children often suffer from detachment disorder because “to be dependent on others is extremely shame producing” and emotionally provocative. They have learned to have a cocoon of self-sufficiency; they hate and mistrust anyone who tries to penetrate this cocoon” because to them it feels dangerous to let go of their hard-won defenses against memories and emotions they were overwhelmed by when experienced originally. “Their behavior is often quite unpredictably aggressive because they learned to soothe themselves as infants. Their brains and bodies have been adapted to self-stimulation and self-soothing behaviors that can appear to be quite odd to others. They beg for attention but resist close relationships,” (van der Kolk 1997).

Parents of preemies do express concern that their children are very impulsive – an impulsivity triggered by the limbic system upon present-day stimuli. They frequently overreact to the environment and may have vision and/or hearing problems. When undetected, they appear disorganized and unfocused. Their behavior is interpreted as willful and uncooperative, but it is chronic anxiety that increases their activity levels. They may be perpetually on the defensive. Some of these children are referred to as “one-five kids.” They go from deep (state 1) to screaming (state 5) bypassing light sleep, drowsy, and alert states. When upset they are hard to console, (LaRossa 2000; Perry 1995) predominantly because they cannot verbalize what is actually wrong rather than what is apparently the problem. To the child, the actuality is that the upset has triggered much stronger emotions than the



situation (apparent cause) warrants because of past traumatic experiences. These children are frequently confronted with the effects of their past traumas by means of associations. For example, a six-year-old may throw a sudden temper tantrum when another child accidentally bumps into him from behind. The startle reflex will activate the limbic system, or emotional brain, and set off the chain reaction of panic, defensive aggression, and screaming. Internally, this child feels as if he is back in the incubator confronted with unexpected pain while choking on tubes and too dependent to handle the effects of trauma. Consequently, they are misunderstood by their care givers. Children having difficulty integrating information they receive simultaneously from two or more senses may appear reluctant to try new activities, including walking, climbing, and jumping. Social interaction – always requiring more than one sense such as visual cues, spoken language, integrating nuances of vocal characteristics – is difficult for them, (Carter 1998). Untreated, they are at risk of becoming loners, bullies, or silent outsiders.

Over time, people develop secondary adaptations to trauma, obscuring the connections between the therapy patients' symptoms and their history. For example, the generalized affect dysregulation, such a detachment disorder, impulsivity, over-sensitivity and constriction of ego functioning is seen in almost all traumatized people. For traumatized infants and young children the complexity grows as they advance and go through different maturational stages (van der Kolk et al. 1996). Each stage can bring a new layer burying the original traumata deeper and deeper into the unconscious. The graph illustrates the process.

A recent ten-year longitudinal study of pre-term infants found that sixty-one percent of these children experience low achievement or special needs in schools compared to twenty-three percent of full-term children who have comparable problems, (Barlow 2000). Other studies found that academic difficulties persisted into the teenage years, (Saigal 1994). A more disturbing finding came from a study by Dr. Adrian Raine of the University of Southern California in which the medical records of 4,269 Danish males from birth through age eighteen had been studied. "The researchers found a strong correlation between these youths who suffered common birth complications and a proclivity toward violent crime later

in life, (Sullivan 2001). At least since 1985, according to Bertil Jacobson, professor-emeritus of the Department of Obstetrics and Gynaecology, Karolinska Hospital in Stockholm, Sweden, medical journals have reported a definite association between adverse perinatal conditions and proneness to suicide and addiction later in life, (Jacobson 2000). Ed Kowalchick of the Association of Boarding Schools reported in *The New York Times* (6/17/2000): “Look at the statistics: binge drinking is up, suicide attempts are up, eating disorders among men as well as women are up, depression and anxiety are up – these are things that kids come to us with.” Can we afford any longer to ignore these findings that there is a connection between the traumas preemies experience in the NICU and such deeply troubling social concerns?

This author is not surprised. Life is a continuum from conception onwards. The brain does need a world to respond to. When that world is hostile and terror-filling during early development then the memories will exact a primal philosophy that links the perceptions about the self, people, life, and the world inseparably to those memories of life in the NICU.

In conclusion, we not only have the technological means to keep micropreemies alive, we also have the knowledge and techniques of intervention to help these children. Early touch therapy (Field 2000), education of parents, physical and emotional therapy for infants (Emerson 1998), Hyperbaric Oxygen Therapy (Montgomery 1999), Sensory Integration (Henry 1997), and anger management are just a few of the treatments available. What is sorely needed is a shift in paradigm: newborns, full-term or premature, are not objects who can be fixed with surgery, tubes, medical procedures, and pharmaceuticals. They are not potentially human. They are human. Endeavoring to keep them alive physically bestows upon us the responsibility of fostering their emotional, psychological, and mental beings to the fullest. Micropreemies may be born to live, but are they to be and enjoy life beyond defensive survival?

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