Living Out the Past: Infant Surgery Prior to 1987

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Abstract: This paper will focus on the infants and young children who underwent surgical procedures without anesthesia prior to 1987, the standard of practice at the time, and the lifelong consequences that remain unrecognized and untreated in this population. Relevant historical context unique to this phenomenon in the human story is critical to understanding the protocol by which the medical profession determined care for the infant. The review of the neuroscience of trauma and memory focuses on primary sensory and affective capacity. Physiologically, the neonate and preverbal child's inability to integrate overwhelming pain and terror proved causative for psychopathology. Research will demonstrate how cognitive, affective, and behavioral developmental patterns continue during the lifespan. Through awareness of the profound violation exacted by medical trauma, a link for the adult between their history and current symptomatolgy may begin to be bridged. Looking at the origins of this legacy may further serve to stimulate current pediatric healthcare consideration of the implications of medical trauma occurring at the most vulnerable and trusting stage of early development.

Key Words: Anesthesia, medical trauma, neurological development, healing trauma,

Introduction

The February 27-28, 2010 Pediatric Psychological Trauma in Infants and Young Children from Illness, Injury, and Medical Intervention Conference opened boldly by bringing attention to the medical dehumanization of children under the age of 18 months prior to 1987 (Chamberlain, 1991; Harrison, 1987). At this conference, Dr. Zeev Kain, Professor and Chair, Dean of Clinical Research, Dept. of Anesthesiology and Perioperative Care, UC Irvine stated, "As you all

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know, not long ago we did not administer anesthesia to infants during surgery. We have come a long way, but we have a long way to go." At no other time in human or medical history has one population been singled out for the exclusion of medical benefits, not by malice but by indiscriminate indoctrination. Doctors trained in surgery and anesthesiology adhered to an entrenched protocol and dismissed the reality unfolding in front of their eyes, every day for 140 years. The continuance of unquestioned belief kept the medical community from accepting their own humanity by consistently denying the primary language of the human race. What transpired in the minds of the medical professionals is a phenomenon worth exploring. However, this paper is not concerned with their minds, but rather with the minds left altered.

The broad implications and resulting consequences of a nervous system in full blown shock due to infant medical intervention, with only the use of an immobilizing paralytic, remains unstudied and largely unknown to the general population. Since no parental consent was needed for a "standard of practice" and the pre-verbal infant could not self-report, the barbaric experience was lost to implicit memory. Today there are generations of people left to endure posttraumatic symptoms from a cause they cannot identify.

Psychiatrist and founder of Intensive Trauma Therapy (ITT), Dr. Louis Tinnin (personal communication September 15, 2010) wrote:

Anyone now 23 years or older who had major surgery as a baby is at risk for chronic post-traumatic illness because the surgery was probably done without anesthesia, which was the custom in most hospitals prior to 1987. Abdominal surgery for pyloric stenosis and chest surgery for congenital heart problems were the most common forms of infant surgery. Together these surgeries are necessary for about 8 cases per 1000 births. A rough estimate of the number of survivors [of these surgeries] during the single year of 1987 (3,829,000 live births) is 30,600. We do not know what proportion of these survivors is now suffering with post-traumatic symptoms but considering the severity of the pain and the helplessness of the infant, but we would expect that the majority of these infants were traumatized.

These statistics account for only two types of surgeries out of multiple possibilities and refer only to neonates (infants up to one month), without the inclusion of children up to 18 months. Dr. David

Breseler, former Clinical Professor, UCLA School of Medicine and Executive Director, UCLA Pain Control Unit, cites the following research from the CDC National Hospital Discharge Survey, "2,310,000, in-hospital surgeries (DeFrances & Podgornik 2006) and 2,318,000 out-patient surgeries (Hall and Lawrence, 1998) were performed on children under the age of 15 in the years 2004 and 1996 respectively" (AGI, 2006, p. 1). Accounting for the increase in out-patient surgeries since 1996, current approximation of pediatric surgeries are increased from 4,628,0005 million per year to 5 million per year. The additional five years between 1987-1992 reflected in the figures below will be explained under the historical context section in reference to Dr. Anand's statement that protocol for surgical anesthesia administration did not change until 1992 (Rubin, 2005).

Adults Affected by Neonatal Surgery Prior to 1987 (1992)

Five million pediatric surgeries per year divided equally amounts to 500,000 surgeries <18 months not accounting for the expected disproportionate front-loading of the early years. Due to less technological intervention from 1936-1992 (19-75 age group) 250,000, half the original procedures reflect an average per year. Considering mortality rates the figure is reduced by half to 125,000. The last variable assumes a group for whom consequences were mitigated by caregiver relationship at 62,500. In this approximate and conservative model 62,000 children per year would have experienced the adverse effects of surgery. As adults today the population subject to early life medical trauma total 3,562,500 (62,000 over 57 years).

To attain the percentage of the population affected per annum, live births were averaged over 57 years. Variances in birth rates were accounted for, in terms of reduced birth rates in some years, 1936 (2,377,000) versus higher birth rates, 1964 (4,308,000) in other years (Dept. of Heath and Human Services, National Center for Health Statistics, 2006). Based on an annual population average of 4,773,600, close to 7% neonates each year may be considered to have had surgical intervention. These figures look only at surgery not the NICU/PICU overall or chronic conditions that involve other challenging aspects of early developmental critical care.

Historical Context

The mid-1800's was a time of unprecedented medical discovery when the combination of ether, nitrous oxide, and chloroform were

found to abolish pain during surgery. As noted by Dr. William Silverman M.D. (1999), Dr. Henry Bigelow of Boston published the first article on the use of anesthesia in 1848. He stated, "the new technique is unnecessary for infants, because they lack the anticipation and remembrance of suffering." Dr. Henry Pierson confirmed the theory in 1852, saying, "babies lack the mental capacity to suffer." To insure immobility, Dr. Samuel Cabot remarked, "the child patient had been rolled firmly in a sheet as a substitute for ether" (Silverman, 1999, p. 106). Before anesthesia, surgery was extremely rare, with only 333 recorded cases between 1821 and 1846 at Boston's Massachusetts General Hospital.

In 1897, a Boston physician was reported to have remarked on surgical procedures pre-anesthesia, equating it to the Spanish Inquisition. He recalled "yells and screams, most horrible in my memory now, after an interval of so many years" (Sullivan, 1996, p. 8). This vivid recollection is a reminder that, whether wrapped in a sheet or administered a paralytic, the motionless child felt extreme pain during surgery as well as during the weeks or months of post-operative recovery.

Studies were done at various intervals during the 20th century to confirm the three predominate medical assumptions justifying the practice of performing surgery on infants without anesthesia. The first assumption, based on limited neuroscience, was the belief that infants exhibited only mechanical reflexes, presuming that the seemingly undeveloped cortex had no cognitive ability to process pain. One particularly significant study (size and duration) was conducted by psychologist Myrtle McGraw in 1941 (Chamberlain, 1991) at Columbia University and The Babies Hospital, New York. She recorded 2,000 observations, both awake and asleep, of 10 pin pricks each to the head, trunk, and upper and lower extremities on 75 infants, from birth (some only hours old) to four years of age. McGraw, despite witnessing obvious distress, concluded that the children's reactions were devoid of any cognitive or affective elements commenting on their reactions as. "consisting of diffuse bodily movements accompanied by crying and possibly a local reflex" confirming the integrity of the standing protocol (Chamberlain, 1991, p. 2).

The second assumption was based on Freud's theory of "infantile amnesia." Freud stated, "What I have in mind is the peculiar amnesia which, in the case of most people, though by no means all, hides the earliest beginnings of their childhood up to their sixth or eight year" (Johnson, 1997, p.1). This theory went unchallenged, allowing surgeons and anesthesiologists the comfort of believing that any long

term effects of surgery without anesthesia was impossible without memory.

The third belief, that infants could not withstand anesthesia due to the immaturity of their regulatory systems made the administration of pain relief irrelevant and its administration considered "unnecessary and dangerous" (Chamberlain, 1991, p. 1).

The logic of the third belief eluded Jill Lawson who demanded to see hospital records after her son's death in 1985. She said, "Somehow it was possible for professionals who perceived a baby as too fragile to tolerate general anesthesia, to perceive that same infant as able to withstand open-chest surgery without pain relief" (Lawson, 1988, p. 2). She became the catalyst for change by petitioning the American Pain Society, the American Medical Association, American Board of Anesthesiologists and the Society of Anesthesiologists, the U.S. House of Representatives Select Committee on Children, Youth, and Families, the U.S. Surgeon General, and 18 other agencies.

Her son required PDA (patient ductus arteriosus) surgery, the most commonly performed operation on pre-term infants. At two weeks, Jeffery, "during his hour and half operation had two holes cut on either side of his neck and one in his chest, he was cut from his breastbone around to his backbone, his flesh lifted aside, ribs pried apart, blood vessels tied off and lungs retracted, tissue stitched together and a "stab incision" to secure chest tubes" (Lawson, 1988, p. 2). He died a few days later, as a result of the shock that overwhelmed his entire system causing his brain to bleed and his organs to fail. The hospital's senior neonatologist responded to Mrs. Lawson's inquiries by stating, "it didn't matter because he was a fetus," explaining that children less than 2 years of age "do not feel pain" (Lawson, 1988, p.3). The long held rationale by the allopathic medical profession that prenates, neonates, and infants did not experience pain because of an undeveloped nervous system and unmyelanized nerves was endorsed by the American Academy of Pediatrics.

In near synchronized timing, Kanjalweet Anand, MD completed his research on neonatal pain perception during surgery without anesthesia, which was published in *The Lancet* 1987 (Anand, Phil, & Hickey, 1987). After witnessing an operation performed under the standard of practice, neonatologist Dr. Anand, refused to accept the brutality of surgery without pain relief and conducted studies at Oxford University from 1985-1987. He documented extreme levels of metabolic and endocrine shock in non-anesthetized infants confirming the existence of triple the level of stress hormones compared to post op anesthetized adults. The conclusion derived from the data successfully

established traumatic stress in the infant patient. As a result of this research and Lawson's persistence, the American Academy of Pediatrics and the American Society of Anesthesiologists both agreed to adopt a new consensus on pain protection for infants in surgery in 1987. Yet believing that the new consensus was not being widely implemented, Anand conducted another study at Boston Children's Hospital in 1992 recording data on babies requiring open-heart surgery (Anand, Stevens, & McGrath, 2007). The result indicated a lower mortality risk with the use of anesthesia. Mortality figures proved to be the red flag that convinced the medical community to fully embrace the new protocol. "There was a quiet revolution after that and babies were given anesthesia," said Anand (Rubin, 2005).

Discussion

To consider the long-term consequences of what Dr. Chamberlain calls, "the single greatest mistake in the whole of medical history" (personal communication, November 30, 2009) involves assessing the results of current developmental neuroscience relevant to trauma and implicit memory. An understanding of the trauma response as stimulant to the pre-verbal experience-dependent imprint, as well as examples of implicit memory, serve to increase awareness of the sentient nature of the infant. Medically based trauma on the level of, "torture," a word used by Dr. Sanjay Gupta (Gupta & Anand, 2008), has not been studied or recognized in the same way as other psychological and physical abuses. Therefore, the objectives of understanding the trauma effect on the developing brain, the reality of implicit memory storage, and the importance of the long-term impacts on this population are considered here in a general trauma context.

Conscious Trauma

Anand disproved the absence of myelination in the nerve cells stating, "nerve tracts in the spinal cord and central nervous system are completely myelinated by the second or third trimester and pain pathways to the brainstem and thalamus, which relay[s] sensation to the cerebral cortex are myelinated by week 30" (Anand, Phil, & Hickey, 1987, as cited by Edwards, 2011, p. 2). The focus of primary or perinatal psychology is on consciousness as the organizing principle of our core beliefs (McCarty, 2009). These beliefs create synaptic hardwiring through cellular activity geared either towards growth or protection (Lipton, 2008). Neuroscience discovered what was unknown

to early surgeons, that a "subplate zone" functioning beneath the cerebral cortex and working in conjunction with the limbic area (the seat of emotion), the thalamic fibers, and the brain stem nuclei together allow for cortical processing by which the infant has a very present sense of themselves and their pain (Cozolino, 2006). From the moment of birth the neonate begins to interpret sensory stimuli to develop cognitive, affective, and behavioral schema, "Physical sensations are the very foundation of human consciousness" (Levine, 2010, p. 133).

Clinical assessment of the senses focuses externally and primarily on the integration of auditory, visual, and tactile stimulation (Porges, 1993). According to Porges, "missing from our language and science is the ability to describe internal states" (p. 12). The communication of interceptors (e.g. sensors on organs) with the autonomic nervous system is largely through the vagus nerve and acts as a scanning system is known as neuroception, functioning primarily to interpret safety, danger, or life-threat. Subcortical encoding informs perceptions that become thought, feeling, and action, moving toward either social behavior or defensive behavior. Under threat the polyvagal branches (referring to Porges' theory of three separate neural circuits within the vagus nerve) activate from a hierarchy of evolution.

The newest nerve branch, *social engagement* connects to facial muscles and the neocortex (Porges & Dyke, 2006). This is the primary initiation for securing safety by the infant, using verbal, facial, and motor affects to engage a caregiver. If socially unsuccessful in a traumatic situation, a "feeling" (inadequately described unmeasured internal sense) (Porges 2006) of betrayal will ensue, resulting in a "shattering of their protective shield with long term ramifications to place trust in intimate relationships" (Lieberman & van Horn, 2009).

Secondly, there is *mobilization*, a hyper arousal in the sympathetic-adrenal system, which floods the body with cortisol, dozens of peptides, and neurotransmitters from the hypothalamus, pituitary, adrenal (HPA) axis. The HPA signals cortical releasing factor (CRF) which increases corticosterone production, quickly becoming a maladaptive feedback loop that can become a chronic state of hypervigilence (Pert, 1997). The infant, unable to fight or flee, engages the parasympathetic system initiating an *immobilization* or freeze. The down regulated central nervous system which integrates with hormonal function imprints a disorganized-disoriented-dissociative coping strategy based on the trauma feedback. Thwarted self-preservation can hardwire a state of dissociative automatic obedience as the only mode of escape from overwhelming arousal (Schore, 2010). The exquisitely sensitive

sensory awareness of both conscious and unconscious, internal and external, experience dependent neuroception is equated to "higher brain processes" (Porges, 1993, p. 15).

Author, professor, researcher, and founder of the country's largest trauma clinic, JRI, in Boston, Bessel van der Kolk describes the essence of psychological trauma as the loss of faith in a safe place from which to deal with frightening emotions resulting in a pervasive feeling of helplessness (cited by Chamberlain, 1991). "Time heals all wounds" does not apply in early developmental PTSD, which destabilizes the sense of self (Levine, 2010, p. 88). Dysregulating, traumatic events occurring during the time of the most significant brain growth, the last trimester through the second year, causes a permanent imprint to a developing neural network of immature synaptic connections (Cozolino, 2006) that can lead to a poorly functioning stress response, overly reactive, with compromised ability to recover, and evident over the lifespan (National Scientific Council on the Developing Child, 2005).

The primary neurological development is almost exclusively in the right hemisphere "the emotional brain" which processes fear, terror, and pain. "What most people do not realize is that trauma is not the story of something awful that happened in the past but the residue of imprints left behind in people's sensory and hormonal systems" (van der Kolk, 2010, p.1). This sets a foundation for enduring problems of interpersonal and intrapersonal stressors with later predisposition to psychiatric disorders and medical diseases (Cozolino, 2006). Survival defenses become chronic impulses relying on a dysregulated nervous system. Reactions are triggered by even insignificant stimuli catapulting the heart rate into a state of hyperarousal in hardwired repetition of the initial fear response.

According to Richard Schwartz (2001), often people who have experienced trauma appear calm yet are in constant turmoil inside. They have learned to acclimate by hiding their inner world. The right brain as the core of self-awareness and self-identity is inherently predisposed to assess threat and enact self-defense. In early trauma, experience-dependent neural pathways wire densely for protection often generating more negative emotions and pessimism later in life (Cozolino, 2006).

Implicit Memory

Dr. David Chamberlain (1991) details the reality of pain memory as confirmed by a mother whose premature baby was shunted for

hydrocephalus, an accumulation of fluid in the brain, with only curare as a paralytic. Large incisions were cut in his scalp, neck, and abdomen and a hole drilled in his skull. Ten years after the operation he will not allow anyone to touch his head, neck, and abdomen where the surgery was performed. The mere sight of the hospital provoked violent trembling, profuse sweating, screaming, struggling, and vomiting (Chamberlain, 1991). "When the nervous system is strained to the breaking point, it leaves the psyche, body, and soul shattered" (Levine, 2010, p. 33).

Dr. Tinnin, treating only patients with trauma and PTSD, has had ample opportunity to observe implicit memory as causative of life diminishing patterns. Sharing his experience in the context of medical trauma he states (personal communication, September 15, 2010),

The symptom picture of the survivors we have treated is broader than the usual picture for post-traumatic stress disorder. Adult survivors report life-long symptoms of anxiety (constant nervousness and spells of terror or panic), hostility (temper outbursts and urges to smash or break things), depression, self-consciousness, distrust of others, and a vulnerability to stress. The life-long aspect of these symptoms leads to the faulty perception that they are personality traits instead of recognizing them as persisting expressions of active survival instincts first elicited by the raw pain of the scalpel. That recognition opens the way to curative treatment of the adult survivor.

Implicit Memory and Physical Health

Adult health was surveyed in the ACE (adverse child effects) study, in the largest initiative ever undertaken (17,000 subjects) to ascertain whether there existed a relationship between early trauma and the leading adult diseases. A partnership of the Centers for Disease Control and Kaiser Permante evaluated individuals within 7 different trauma categories. After a decade the study established that early trauma is implicated in the leading diseases and may shorten the life span by 5-20 years. The determinant variable in reduced mortality was dependent on evidence of one or more stressors (Felitti et al, 1998). Veterans returning with PTSD have also largely been found to have experienced early life trauma, which has affected their resiliency and predisposed them to more profound maladaptive responses (Murray, n.d.). Since medical trauma was not a category in ACE, it is unknown if it was foundational as part of the schema of anxiety, depression,

suicide, or substance abuse correlated in the data.

Harvard's Center for the Developing Child research published in JAMA, June 3, 2009 recognized "that early experiences are built into our bodies" and literally "shape the architecture of our brain" (Shonkoff, Boyce, & McEwen, 2009, p. 2252). The article stated that "many adult diseases can be traced to negative experiences in early life, so confronting the causes of adversity before and shortly after birth may be a promising way to improve adult health and reduce premature deaths" (p. 2252). A severely dysregulating experience produces a chemical signature called epigenetic modification. The marker damages the expression of the gene by effectively turning it on or off, altering response to adversity later in life and diminishing personal potential. "The discovery of the epigenome provides an explanation at the molecular level for why and how early positive and negative experiences have a lifelong impact" (National Scientific Council on the Developing Child, 2010, p. 2).

Further Literature Review

The theories of former Stanford University professor, researcher, and cellular biologist, Bruce Lipton, PhD, and Stephen Porges, PhD, University of Illinois, Chicago, professor of psychiatry and Director of the University's Brain-Body Center although appearing divergent seem to conclude with similar concepts. Porges & Dyke's (2006) article confirms conscious awareness in the infant from a sensory perspective using broad qualitative research. Whether, as Lipton (2008) describes, external energy creates beliefs that wire brain function or as Porges posits, responses to internal neuroception create beliefs that connect the neural circuits; they both point to cognitive, affective, and sensory perceptual awareness. Whether the mind's responses precede the neural architecture is scientifically unknown but what is known through neuroception, sensory or cellular, provides a framework by which to comprehend the sensibilities of the infant.

Trauma as a term lacks specificity but in context of Porges' Polyvagal Theory and ANS (autonomic nervous system) integration, the sequence of somatic reactions as precursors to trauma is clarified. Shonkoff and colleagues (National Scientific Council on the Developing Child, 2010) article differentiates tolerable stress from toxic stress that shocks the system with cortisol along with other damaging stress hormones. A brief challenge for the child, such as meeting new people or getting a shot, can be tolerated and managed with parental support. Toxic stress overwhelms the nervous system

and initiates the vagus nerves' tripart trajectory building set points of hyper or hypo arousal.

Lieberman and van Horn's (2009) article states that "there is a widespread misconception among health professionals and the public at large that young children are immune to trauma because they are too cognitively immature to understand, remember, and be affected in other than a transitory way by violence, accidents, intrusive *medical procedures...*" (p. 707). The significance of incorporating the context of early development rather than simply focusing on behavior is emphasized by Lieberman, PhD, Chair Infant Mental Health Department of Psychiatry UCSF and director of the Child Trauma Research Program, and calls attention to the importance of consciousness and implicit memory in the therapeutic and medical setting.

Psychologist, Dr. David Chamberlain, (1991, 1995, 1998, 1999) author/editor, founder of Birth Psychology, and former president of APPPAH, continues to pioneer prenatal and perinatal consciousness by debunking the myths that have kept infants constrained within the artificial limits of disbelief. Observing and recording behaviors in the fetus and neonate his view is direct, "A fundamental rule of developmental psychology that all complex behaviors must start out as simple behaviors and develop gradually has become obsolete. Surprisingly many behaviors start out complex" (1998, p. xiii). His rejection of the long held denial of pain in the infant is uncompromising, "Pain is a universal language that can be understood by its vocal sounds, facial expressions, body movements, respiration, color, and even its crashing metabolism. Babies speak this language as well as anyone. We should listen seriously and react appropriately" (Chamberlain, 1991, p. 2).

Interpersonal Neurobiologist Dr. Schore, Department of Psychiatry and Biobehavioral Sciences, UCL David Geffen School of Medicine (2010), describes somatoform dissociation in reference to early onset trauma involving physical abuse and threat to life (both found in medical trauma). The frequently resulting PTSD reflects a "severe dysfunction of affect regulating and stress modulating functions which, in turn, impair the capacity to maintain a coherent, continuous, and unified sense of self" (p. 5). His position is clear and poignant, a child whose developing right brain experiences an acute impact to the limbic area, which is most associated with right brain function, will become an adult who suffers "a progressive impairment to the ability to adjust, take defensive action, or act on ones' self-behalf and a blocking of the capacity to register affect and pain, critical for survival.

Ultimately people effected by early trauma experience themselves as different ...as well as unworthy of meaningful attachments" (p. 83). Dr. Schore describes the complex and compounded long-term consequences this paper seeks to illustrate.

The relationship of early trauma to adult health as seen in the ACE study is an example of somatic and cellular memory, where deep within the nucleus of the cells the epigenetic modification locks in the trauma exemplified in the study. The detractors of the ACE study suggest that behaviors such as substance abuse or smoking were causative of lung disease or cancer, which, while valid, does not consider that the tendency to self-harm may well have its origin in early childhood adversity.

Conclusion

The 2010 International Society for the Study of Trauma and Dissociation's five day conference offered over 150 workshops and attracted nearly 500 participants. With many of the world's most renowned experts presenting, not one reference was made to medical trauma, nor could more than a mention be found among the staggering quantity of books on sale. The DMS-IV-TR does not list it as causative, in any age group, for PTSD but defines parameters as, "exposure to an extreme traumatic stressor involving direct personal experience of an event that involves actual or threatened death or serious injury, or other threat to one's physical integrity" (APA, 2000, p. 463). Characteristics include "intense fear, helplessness, or horror (or in children...disorganized or agitated behavior)" (APA, 2000, p. 463).

Childhood experiences are the agents that drive who we become and how we interpret and execute our choices based on perceptions of safety or fear. The research shows that our earliest foundations can lead us to an affective entrapment between overwhelm and shut down, if trauma is not treated. The conservative approximation of three to four million adults, in this country alone, who are suffering the effect of fundamental neurological changes shaping their relationships, world view, and life course as described by so many experts, have an undeniable right to understand what implicit forces may be corrupting their resiliency and impoverishing their potential.

Changes in cognitive neural pathways, dysregulated autonomic and central nervous systems, affective limbic system maladaption, decreased hippocampal capacity, hormonal and neurotransmitter imbalances, impaired social connections, and physical disease are only some of the reasons why medical trauma can no longer be dismissed

as less than severely problematic. The importance of reaching the adults subjected to medical trauma as infants is of no lesser or greater urgency than other mental or physical abuses, disorders, or pathology.

The nexus of this issue rests in the unstudied, unrecorded, and untreated population that deserves the opportunity for improved psychological function through recognition of the trauma that they have never consciously known and never subconsciously escaped.

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