

TRAUMA AND DRAMA IN 13-YEAR CAREGIVING OF SEVERELY BRAIN-INJURED SON: A POETRYSyed Tajuddin Syed Hassan¹, Husna Jamaludin²

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TYPE OF ARTICLE: AUTOETHNOGRAPHIC POETRY**ABSTRACT**

The inspiring movie “The Big Short” posits truth as poetry, although many people do not like poetry. However, poetry sparkles like the opening of a flower, imbued with beauty and mysterious biological and natural phenomena. Reading poetry can promote social bonding and soothing of the mind. Moreover, poetry comes alive with emphasis and rhythm embedded within word inflection, intonation, and rhymes. Hence, elements of poetry, such as creating mental images, diction, form, cadence, rhyme, rhythm, stanza, and verses, are selected and generated carefully and seamlessly embedded here. Quality characteristics, such as imaginative, creative, thought-provoking, figurative language, and experience-empathizing characteristics, are also emphasized. The theme of the poetry presented here encapsulates an evocative auto-ethnography of caregiving for a severely brain-injured son. It portrays the drama and trauma in a 13-year period, commencing with the initial time of infliction of the traumatic brain injury. Over a 10-year period, continuous recordings of events and happenings and of oral and visual events enable snapshots that integrate and synthesize the entire “story.” The poetry contains a number of stanzas (paragraphs), i.e., the emotional and physical tsunami at the beginning; despairing the loss of our second son; imploring divine intervention and salvation; sojourning in the intensive care unit (ICU) in a minimum state of consciousness; the ICU setting and its surrounding; life’s quandaries; reflections on quagmires of the mind; the healing process and rehabilitation; and subsequent long-term trepidation. The underlying auto-ethnographic account is predicated on the critical analytical practice (CAP) methodology of Carolyn Ellis. This poetry is narrated in the present tense, thus evocating immediacy and intimacy. We believe this poetry evokes peoples’ emotions and informs them of the overwhelming demand of caring for a severely brain-injured person, hence sensitizing and uplifting their perception and understanding towards the process and task of caregiving.

KEYWORDS: Autoethnography, Poetry, Traumatic brain injury (TBI), Caregiving, Aging, Rehabilitation

1. THE EMOTIONAL AND PHYSICAL TSUNAMI

13 years ago: A long, long time since then, to frame and to beam...every emotion, every dislocation, every trauma, every drama ...every pain...every claim of swollen brain, dislocated joint, cracking bones, pain-suffering groans, crunching-swirling-piercing mind, crooked behind, hollow blinks, and broken dreams. Traumatic brain injury ... silent... aggressive calamity; torrid disability, acrid dysfunctionality, horrid disorientation, toxic sensation, morbid spasticity...abysmal destiny. Our family life’s normalcy drowned by destiny’s continual tsunami! God, are you listening...we are drowning, sinking! Why does this continue to happen? That fateful day...seems yesterday, that moment of life’s inflection...destiny’s intervention, that moment of entering the dark tunnel of life...will there be light at the end of our strife? That day, life is sucked... swallowed by fate’s black hole...swirling, spinning, pulling, violent growling; a heavy toll enslaves our soul, floats blankly, aimlessly with no port at which to dock. It frets, the physical self-shreds, thoughts racing, darting, bending, cornering, pulsating: aimlessly, vision blurs numbingly, the mind dumps, slumps, meanders, swerves, numbs self-bled...everything dreadfully bad; That day...the longest painful day...wounded heart laid bare... so rare beyond compare...the world, the entire universe crumbles, planetary systems rumble... life muddles... life’s mission-vision ripples...dream-mountains topple. That

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day...everything...preambles rest of life's blurry drudgery rumble...!? Doomsday...life tumbles...twirls...flays...decays...to rubble...

2. DESPAIRING THE LOSS OF OUR SECOND SON

Demise never revive one son, survive... the impaired one; wrenchingly painful loss...life's destiny at a cross...tearless cry...didn't even get to hug him goodbye...no more of his endearing antics, witty polemics, one-liner wits, and cheerful drop-by, even for a short while...yet have to endure...unrelenting, excruciating heart-wrenching adios... our hearts never endorse...but cannot indulge into morose; ...with severely brain-injured of another, our life's system warps yonder, life-normalcy-orchestra's rendition, harps and conjures chaos... out of order bios: but there is no choice- but why us? And, not others?! Sounds callous and ungrateful not accepting God's-sanctioned fate...destiny...blasphemy? Little dissenting voices in us continue to berate, to desecrate...why us, why me? Hollow clingy answer-soliciting echoes keep pinching our mind daily...never froze...

A sea of swirling emotions continually drowns and engulfs our existence. We do not envisage and prepare for such family-life's sharp inflection. We swim emotionally, physically, erratically, frantically through turbulent seas and oceans...of life's dimension... seeking shelter and solace, wanting solutions...yet...wondering, where is our life's direction? Lots of prayers, soliciting divine intervention, enticing salvation...but alas, continuing tribulation. Not giving up, some uplifting hands, some help...but, by and large, our own frantic crawling, inching to rehabilitate our son. Hell on earth; what do we have to do in earnest? Where do we start first? This life's epiphany we have no clue...let alone excel what to do! His brain is in a coma (?); we are embedded...shackled...studded...stuck... in this life's drama. Our twinkling mind pops, "Dear God...please help us...save his life...show us some light in this relentless journey's dark tunnel with no prize." Nonetheless, we hold our hands high, arms-length, back and front, to exude strength to our life-battling son.

3. IMPLORING DIVINE INTERVENTION AND SALVATION

We faced a three-month sojourn in intensive care for him, and a subsequent one year of brain entombment, the "minimum consciousness state (MCS)...Is MCS the brain forcing itself to rest? With trembling soul, we steer our steely, but shaky, hold...vibrating heart ...it's so hard...moved every fiber...strenuously saviour... every grain of brain, to think and every strand of muscle to wake him...yet wobbly silently growl...no...no... never surrender to fatigue or bleak, challenge our fate that's our unsolicited role with no fret. So precious and rare is life-on-the-edge-moment...almost like an omen...the ensuing long-term arduous painful rehabilitation. Enmeshed and juxtaposed with prickly endearment...our only living son, who has no one else to turn to and nowhere else to run through. A quandary, a quagmire...a checkmate...but, not dead, yet our fate seems so dread! That is caregiving a brain-injured son. It goes on and on, day and night, in darkness in daylight...sucking all your foresight, hindsight, right, and might... There is no respite! Bittersweet pills to swallow...no room for appeal or to wallow! There are overwhelming demands to command and frantic schedules to rule. Yet no mistakes can be tolerated...no fumbles be toggled...'cause errors portend life's calamity...disastrous...certainty. Caregiving success, rehabilitating and mind-mending, tantamount to scaling Mount Everest. One's mind torments, demons...never rest. Dear God...we implore for a life of bless...

4. SOJOURN IN INTENSIVE CARE UNIT (ICU) AND MINIMUM CONSCIOUSNESS STATE

The ICU setting and surrounding, so vivid in our mind, so livid in time, forever appearing, replaying...never distancing, nonchalant and menacing. Stifling sick peoples' aroma-odour, and dreadful stench of medicine...so permeating-nauseating, so pervasive...so invasive, so repulsive, so overpowering, never enticing...smelly anaesthetics so revolutive... unnerving quietness, numbing coldness, eerie silence, heavy breathing of patients...forever persists with uncanny precision... hissing sound racing against breathing machine, man and woman in white robes murmuring. On well-spaced-out metal beds...closed-eyes sleeping heads, occasional groans...bemoans "I am so alone;" tangled criss-crossing tubing and wiring dangling everywhere to nowhere. Light purposely dimmed (?) entice fright, yet without remission...every breathing body focused of attention...every breath, every hissing may be the last, for the body fully stretched. Eerie place to reside...every day, at least one, with closed eyes forever, come-back never.. quickly covered and hurriedly carted out on trolley, departed...families grieving audibly heard. Return to God...life has expired.

Drown and surround... pain, yet, with all might, tenacity, riddled with fright ...unflinchingly frighteningly braving, not a bane...never in vain... despite clinging cringing pervasive mental sprain; we cloak on brave faces, take deep inhalation, and stoically strategize ways for his rehabilitation. Heaven on earth...diverse choices abound in earnest...

lives not a continuum of empty-ness empty-nest. Amidst worries and quandaries, life is taking risks! An inner voice decrees... "Come on, never a cowardice be...go...even to the edge of reality if need be" ...Clinching our resolve, we do not flee. Be there gallons, buckets of tears...hope- beyond illusion, prayers, and serenity through spiritual serendipity, overcoming trepidation ostensibly. With exploring of healing through incessant gropes, muddled by anxiety and start-stop-recover calamity...yet we resolve, we will never defeatists be...

5. REFLECTIONS ON QUAGMIRE OF THE MIND

Replaying reflecting: Your son will be a vegetable...mantra of the specialist and wannabe. Deep in our (as parents) hearts ...we proclaim this cannot be. Replaying reflecting; thus begins life's epiphany...inception laced with travails, tribulation and agony; how can we be free? Facing lifelong daunting-jaunting journey...encroaching-poaching edge of reality...overwhelming responsibility yet below-par knowledge and understanding. Empowerment to parents.....so they say...the power that be.....you're on your own...that's the reality. You hear the shouts; we are a caring lot...society...empathy, sympathy...to the brim: really?... You shudder, perplexed, wonder...what does these all mean?!? The shouts so loud, pervasive, convincing...yet hollow ream enshrouded and embedded with shallow dreams.....You cringe.....gulping bitter pills...with no glee...with no blink...with steely resolve: recovery glows. With inching progress...with millimeter regress...drenching our action-emotion with pain...stay on train...and with herculean duress...but continuing emotional heist...Is it God's Bless...or... Nature's Zest? At its worse, Atonement for sins- mantra of puritans...we are perplexed... why this blame? God-chosen Job, himself, has been tested with utmost suffering and pain! Redemption? Our inner voice nags, "Why me?" Someone quips, "you're chosen, you're resilient "...a deva? A sharp pang almost shatters our steely qualia.

Since then, 13 years ago, life's been a roller coaster, of normal and abnormal time-capsule scattered clusters...whatever/whenever/wherever...continually-continuously the mind twirls, shudders, jitters and throttles; are there left any sparkles? For the caregivers, him, and our son, the care-receiver ...God, please lead us out of this quagmire. We grope, probe, in darkness, and tumble- somersault, twirl, groping, trial-and-error eating-dieting-medicating-healing with no stopping. Truly, severe brain injury is a hideous disease without bliss; sensualizing, perceiving, thinking, synchronizing, ... jumbling, randomizing; ceased. Our rational mind jostles, rumbles, crisscross and twists. Almost as if a long, emotional sensorial journey riddled with silent fracas...an unending sojourn of convoluting winding physical-mental-spiritual entrapped heist.

6. THE HEALING PROCESS AND REHABILITATION

13 years on: Continual rehabilitation, gradual incremental recovery...proves specialist prognosis blurry, uttered in a hurry! Where do they get their degrees? (Give parents' worst scenario...let them do the worry?). Empathy, caring society: rhetoric's, rhetoric's, rhetoric's...meaningless euphoric: the DNA of contemporary society; who are we? Dawdling peoples' fate and quale? Truly, severe brain injury, a horrendous impairment- every functionality in and on the body- ostensibly becomes ugly and awry! God dear- make him recover; us caregiver, not forever! Implore we must, make him recover...not ever...next to never...Are you soliciting our redemption? Our mind jostling and probing...retribution?!? In time, though, God's invisible salvation, beyond expectation, beyond health professionals' vision, sparkles through incredible healing-rehabilitation. Brain healing: continually progressing- though now-and-then regressing. Yet true to a kind, un-readied mind deludes mending minding. Other healings bloom: attribution, affections, cognition, recognition, ostentation, sensations, empathy, and sympathy, physical and emotional sensation- all, appear, at times disappear, transitionally with no conditionality.

7. SUBSEQUENT LONG TERM TREPIDATION

All in one, reflecting and projecting daily, wearily, what happens next, when we, the parents, are no more near here...to love, to care, to nurture, to spur... hope and prayer...that is our main worry! Until death do us part...our only available mantra from the heart! Dysfunctionality for eternity? Destiny enticing cruelty? Dead silence...no response to our minds' bubbling see-sawing credence. No glory in brain injury; little empathy, minute sympathy, in caregiving lifelong disability. No antinode for our anxiety! Does family, does fraternity, does health authority, does polity, does society...really cares, sincerely? Dictum dictates...injured brain pains, deranges, drains, injured mind blinds and redefines! Appeasing salvation but with no option; life's rhyme weathers through storms, torments, and mines...Amen.

CONFLICT OF INTEREST:

There is no conflict of interest to be declared.

AUTHORS' CONTRIBUTIONS:

Both authors contributed to this article equally. Both authors read and approved the final manuscript.

REFERENCES:

This is a poetry article and does not have references