

Aging parents' caregiving and rehabilitating a brain-injured son: an autoethnography of a 10-year journey

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Abstract:

This autoethnography withdraws from information accumulated through a 10-year period of daily-weekly-monthly descriptive observation-recording (triangulated- parents & house-helper) of caregiving and rehabilitating of our brain injured son (survivor/care-receiver). We present it as an interactive voice of verbal conversation, thoughts, insights, and interpretations. It is delivered as a series of articulation intra-pulsated with our interrogation of societal-cultural-religious perspectives, norms and biases, and aligns with the CAP (Creative Analytical Practices) method of Ellis. This autoethnography glows from the richness of information which encapsulates the challenges confronting us the aging parent caregivers, the gradual incremental mind mending achievement of our son, and the interactive verbalizations and thoughts, of the caregivers, care-receiver, and other persons. The overwhelming mental and physical pain and struggle of the survivor and the aging caregivers and their sense of celebratory-satisfaction with rehabilitation progress are highlighted. Interpretation and valuation of positive and negative responses of other persons provide a critical matrix to this autoethnography. We intend to inform other caregivers and relevant healthcare professionals through this autoethnography.

Keywords: autoethnography, traumatic brain injury (TBI), caregiving, aging, rehabilitation

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1. Introduction

Autoethnography is fundamentally a self-reflection entity with qualia deliberations, comprising research, writing, story, and method (1) that explores the researcher's personal life experiences and relates the story to normative perspectives and matrix of culture, politics, and society. It is widely accepted that story telling is a basic and essential form of human communication. For brain-injury caregiving, stories delivered by the actual caregivers are relatively few compared with stories narrated by a third party (2). Traumatic brain injury (TBI) due to motor vehicle accidents is a major and increasing world concern (2-5). This autoethnography illustrates aging caregivers' challenges in rehabilitating a brain-injured son. The published literature, based mostly on quantitative research, has focused on TBI patients, their treatments, and their rehabilitation (6). Nevertheless, to fully understand the challenges of TBI healing and recovery, it is imperative to unravel the caregiving and rehabilitation processes, giving due recognition to the challenging role and experience of the caregiver(s), especially aging caregivers. These challenges and tribulations are exacerbated in time with aging parent caregivers. Moreover, dynamic verbal communication and interaction have not been addressed properly and highlighted in the literature. In societies with

native Asian culture, autoethnography has been properly documented only on rare occasions. This autoethnography should inform caregivers and health professionals to enhance their relevant and respective roles in caregiving and rehabilitation of TBI survivors.

2. Our autoethnography

2.1. Setting and method

We situate and deliberate this 10-year, daily-weekly-monthly descriptive observation and recording of our activities (triangulated through parents and house-helper) as a single descriptive case study, as a voice of conversation, and deliver it in the present tense to evoke the sense of immediacy and intimacy. This is a common practice in autoethnography. This autoethnography, delivered as a series of articulations intra-pulsated with our own interpretations, aligns with the Creative Analytical Practices (CAP) method of Ellis (1). Such interactive communication between us as parent caregivers, our son, and concerned others glues the exchange dynamics during the caregiving-rehabilitating process (7). Major challenges and achievements are embedded (8), despite many unfulfilled needs and wants (9, 10), which are expressed through the thoughts, feelings, and verbalizations of the caregivers and the care-receiver. These are interwoven, thus engendering the “richness” of their interactions. We interrogate socio-cultural and religious values and perspectives, and we posit our own interpretation and judgment, thus lending an analytical frame to the autoethnography. Evidently, society is unaware of or nonchalant about our challenging trauma (especially the mental component) (2), the gradual healing of those with TBI, consequent sequelae, and turbulent experience and needs of the caregivers and the survivor (11). Perseverance through God’s help and salvation is critical and essential on this perpetual journey. This autoethnography may resonate with other caregivers and survivors in similar dire situations, and, we hope, uplift their spirits. Also, perhaps it will enlighten healthcare professionals and enhance their practice of healthcare.

2.2. Conviviality and cynicism

A three-month coma followed by the consequent nine-month minimal consciousness state (MCS) truly entombs the mind of an injured brain, the TBI victim. In the subsequent two years silence prevails. Nevertheless we witness voices trying to break out, through the body language, initial spelling attempts, gestures, and kinesics’ expressions. These unfold as the struggle to communicate intensifies (12). From then on, intermittently, but with increasing frequency, the mind of the brain-injured care-receiver speaks out. In time, a long time, the brain-injured mind progressively mends and heals, though not completely, and the entombed mind unfolds. The caregiving and rehabilitating jobs simultaneously heal the mind and initiate gradual recovery of other physical and cognitive deficits. These tasks become increasingly challenging for us parents and aging caregivers (13).

“Your family is especially chosen by God to endure this double-trauma experience. It is a gift and a challenge given to prophets to test their patience and steadfast immersion in God’s will.” That statement was offered by a friend who was trying his best to exalt our status and comfort us concerning that fateful day, January 31, 2003, and the ensuing responsibilities. Being convivial through words that placate a person or family in distress is Malay, if not Malaysian, cultural artifact and pleasantry. In that fateful accident, our first son, R, sustained a severe form of traumatic brain injury (TBI), known as diffuse axonal injury (DAI), and our second son, E, died.

“God knows both of you, husband and wife, are strong people. Hence, God delivers you this challenge,” someone else reassures us. “What are these people talking about!?” ST’s (R’s and E’s father) brain rebels grudgingly. Our hearts pump thunderously and erratically with anxiety and sorrow. “Dear...God...We are not that strong...please help us!” Quietly, and in a somber mood, ST pleads for divine intervention. On a contrary note, remorse with a faint ambient and transient despair surfaces “I wish we were not that strong! We are getting old fast!”

“...wonders what fault we sometimes commit on this Earth,” another puritanical person quips with a cynical, yet meaningful, jesting of one’s mind, as if saying, “You and your family have sinned. Now, God is justifiably punishing you!” The statement is excruciatingly painful for H (R’s and E’s mother) and ST to hear. Wow...Uh...quietly and reflectively H and ST synthesize and conjure an appeasing perspective. “All prophets have been challenged with torments and hardships, which have been laced with emotional, mental, and physical pains...have they committed unforgiveable sins?” Is this a conjecture? A blasphemy? More thoughts wedge their way out of our tightened and twirling minds...“If sins determine the intensity and veracity of inflicted pain and trauma, the “forever-sinning” people of gambling places such as Las Vegas (with all due respect to LV) should have been punished with miserable lives, perpetually” (21).

People's comments alternated and inter-mingled with ours, the caregivers' response of thoughts, perceptions, and reflections. "Why do human beings always blame misfortunes on sins and punishments? Doesn't God's design of life's destiny and accountability exude challenges, pain and resilience?" We resolve to focus on R's rehabilitation and the healing of his mind. Other people's negative comments do not matter. Thus, we situate this narration through many of our communicative interactions with R, and we use our own interpretations to bind the narratives and synthesize the subsequent implications for rehabilitation and healing of the mind. These brain-injury sequels of challenges produce rehabilitation achievements and milestones that emanate warmth and joy in our hearts, the caregiving parents. There are many of these moments, although at times they seemed hidden, especially during the first five years. Moments of happiness and enlightenment bloom especially when help, assistance, and support emerge from unexpected quarters. For aging caregivers, these are specks of treasures in a vast ocean of outcome uncertainty and pervasive apathy (13).

2.3. Moments of reckoning

Suddenly, out of the blue, during year five after R's TBI, while browsing through a man's health magazine in a bookshop, R retorts "I would rather build my brain than build my body." Truly a first mind-sparkling, words-of-wisdom moment! Similar witty, one-liner remarks that indicate eruptions of thoughts and feelings litter this journey of R's rehabilitation (14, 15). Evidently, R's reasonably high IQ make a difference in rehabilitation. At times ST's mind explore, "Am I witnessing God's greatness through this re-creation of a brain-injured mind? If so, then, this is a rare and precious gift that should be disseminated widely and shared by others, especially those who are confronting similar challenges and tribulations in life."

We knew by the fifth year that R's level of awareness and consciousness had reached a respectable milestone that would enable him to propel to a higher level of cognition (16). He was ready, then, for more intensified physical, neurological, and socially-affective therapies. He continually surprised us with his one-liner words of wisdom. "The problem with me is I have two brains: The normal one and the stupid one," R blurts out nonchalantly, yet forlornly, while playing chess game against ST (that R won). Profound statement! This must be an awakening moment of reckoning, the realization of the impact of his brain injury and the accompanying disabled condition. H and ST agreed that such realization is tantamount to a moment of gratification for us, the caregiving parents; we have done right for him in this long arduous journey of rehabilitation. One day, while watching the news on TV, R quips in a rather disdainful tone with a wrinkled forehead, "I don't understand politics anymore; there are so many twists and turns." Such a high-level, cognitive statement warms our hearts.

2.4. Irony and epiphany

Incremental achievements, however small, are meaningful to a brain-injured person, as well as to aging caregivers. The irony is that our society undoubtedly judges progress in brain-injury rehabilitation through the lenses and perspectives of normal human beings. It is a pleasure of indulgence that we take for granted. If only we could see through the lenses of brain-injured people, our perspectives of their achievements and progress would be drastically different; small improvements are viewed as big advances. In R's case, we witnessed and rejoiced in his sequential series of rehabilitation progress...some with unbelievable levels of healing and restitution, knowing the severity of his brain injury...: opening his eyes, sensing and responding to tactile, oratory, olfactory, audio, and video stimulation, healing of auditory perception, gaining of awareness from his minimal consciousness state, recognizing the Roman and Arabic alphabets, initiating communication through spelling and sign language, improving cognition, gaining ability to read and write, enabling greater attention and focus for longer durations in watching television, initiating playing chess, smiling and laughing heartily, taunting and joking, showing capability of empathy and sympathy, eating and munching of reasonably chunky food, attempting his own feeding, lifting his formerly semi-paralyzed right hand and leg, conversing and commenting while and after watching video and movies, Internet roaming seeking an international opponent for a chess game, intent surfing for socializing, and expressing remorse (15-18). A most memorable instance during the seventh year of his recovery was when he admits with a forlorn and longing sober face, "I have not prayed for a long time." Wow.....a spiritual awakening...in the seventh year.

2.5. God's sanguine gift ...serendipity

During year nine after his TBI, for a number of days, R continuously complained of having problems with his vision. He refused to read for days or watch TV for an extended duration. When solicited to describe his problem, R spurts out "I am seeing two of every one thing. I cannot read, I cannot see TV clearly." Although we were slightly jolted by this vision impairment, we were not in complete shock. ST looked straight at R's face and observed that

his right eye was focused straight ahead, but his left eye was focused to the side, which caused divergent vision to emerge. True to the literature's prognosis, TBI affects multiple functions, including vision. We were witnessing the unfolding of the sequel of brain-injury impairments.

"Don't worry..." ST comforts R, "we'll take you to see an eye specialist." At the back of ST's mind, he badly needs to appease himself since he knows the eye specialist is his office colleague, a medical doctor with a specialty in ophthalmology. ST finds comfort, too, in God's words in The Qur'an... "To every issue, problem or challenge, there is always a way out." After substantial consultation and check-up by the ophthalmologist, we were told "The only way to rectify R's vision problem in the long term is through surgery...or...to wear an eye patch on the eye with the deviant focus. The ensuing one eye vision, though, produces flat images without any depth or 3-D view."

Wow...what a choice! Eye surgery? Eye patch? Eye surgery sounds frightening. Wearing an eye patch conjures an image of General Moshe Dayan. These thoughts raced back and forth in our minds. For moments subsequent to the ophthalmologist's assessment, we were speechless...dumbfounded...in a stupefying quagmire! Somehow, we managed to regain our courage, and we thanked the doctor and said, with drooping hearts, "We'll think about it and discuss it", and if surgery is the choice, ST would tell him. Deeply...we prayed for divine intervention and salvation. Questioning thoughts darted in and out of our minds...how to heal this vision impairment...is it possible at all...if not what's the next step we should be thinking about...our thoughts kept on swirling and twirling. Consequently, we continually prayed hard, begging God's salvation. Lo and behold, divine intervention does come in mysterious ways. A billion to one chance occurred when we were at a shopping center; an oncologist noticed R's condition and invited us to try an innovative treatment called bio-resonance.

Conflicting thoughts swirled in our minds...again. Is this bio-resonance real? After some checking and investigating, we decided to give it a try. What a joy... subsequent to six 20-minute bio-resonance treatments, R no longer had double vision! An alternative (1) healing treatment...and it worked! What a happy ending to a 10-year journey...end of 2012...in caregiving and rehabilitation. Despite the provision of structured efforts and facilities (19), serendipity through God's salvation led to light at the end of a dark tunnel. ...Seems a far cry from the despair-gloomy scenario of a no-hope diagnosis and vegetative prognosis of January 31, 2013! Surely, through God's will, perseverance in moments of turbulence does lead to triumph. Undoubtedly, through insight, this long arduous experiential journey glaringly indicated the need for a global enlightened society that embraces understanding, empathy, and sympathy towards TBI survivors and their caregivers (20).

3. Reflexion

This autoethnography unravels the marvel of perseverance, tolerance, and God's salvation through prayer, of bio-resonance, and of society's ignorance. Here we are not pointing fingers towards anyone who does not understand us, the caregiver and the care-receiver, in this tumultuous journey of TBI caregiving and rehabilitation. Society must be enlightened about brain injury, its sequelae, the rehabilitation process, and trauma-causing quagmires. This can be addressed through qualitative research followed by deliberation and promotion through self-narration and reflection, such as autoethnography, which is aligned with the critical analysis practice method that ensures the critical analytic approach of the story. Only then will people know how to react, respond, and communicate properly, graciously, and with empathy towards TBI survivors and their caregivers. Evidently, this autoethnography beckons to a global society that really cares.

Conflict of Interest:

There is no conflict of interest to be declared.

Authors' contributions:

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

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