

Neurodivergence Enminded/Embodied: Living with Severe Traumatic Brain Injury

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Abstract

This article positions my experiences as a severe traumatic brain injury (TBI) survivor relative to other TBI survivors and in context of persons with disabilities (PWDs) living in the United States and the world. This autoethnographical account (by autoethnography I understand a method or form of social research that serves the purpose of exploring personal experiences of the researcher) examines the life of a neurodivergent individual whose brain functions in ways that deviate significantly from social norms. I explore profound changes to my identity and the resultant social disconnection I encounter since acquiring a severe TBI more than a decade ago. The profound alterations to my identity affect my ability to process, and then adjust, to the demands of my surroundings. As I decode, decipher and process the world, at times my brain damage triggers and/or produces episodes of temporal dissonance. As these shifts in timing occur, they have tremendous impact on my emotional stability. Despite these outward difficulties, I celebrate my altered awareness of time and new identity as a disabled person. Connecting relevant critical trauma studies scholarship to the themes addressed here, the article examines how moving through trauma, coma and amnesia to a new life with cognitive, emotional, psychological, and physical impairments importantly enriches expression of my humanity. I will demonstrate the salient aspects of my new life – emotional sensitivity and volatility – may on the surface seem detrimental and undesirable; however, these qualities greatly enhance my identification with and empathy for others, which in turn drive my artistic, social, cultural and political expression, along with my quest for community.

Keywords: *traumatic brain injury, acquired disability, identity*

This article explores personal stories of trauma, coma/amnesia, physical-emotional injury and recovery from severe traumatic brain injury¹ acquired during an automobile accident. I examine how the confluence of acquiring severe traumatic brain injury and exposure to disability studies concepts/paradigms, while pursuing a graduate degree, catalysed emergence and triggered establishment of my new identity as disabled.

First, I provide an analysis of the social context for my stories of survival. With an estimated 10 million occurring each year, the World Health Organization (WHO) projects traumatic brain injury (TBI) will surpass many diseases/disorders and become the major cause of death/disability by 2020.² The WHO reported aetiology of traumatic

¹ Severe traumatic brain injury is commonly referred to a loss of consciousness or coma greater than 24 hours, post-traumatic amnesia greater than 24 hours, or abnormal brain imaging results; available at <http://www.northeastern.edu/nutraumaticbraininjury/what-is-tbi/severity-of-tbi/> [accessed 20 June 2018].

² Adnan A Hyder, Colleen A. Wunderlich, G. Gururaj, Prasanthi Puvanachandra and Olive C. Kobusingye, 'The Impact of Traumatic Brain Injuries: A Global Perspective', *Neurorehabilitation* 22 (2007): 341. Review of literature determined inconsistent international standards to support longitudinal

brain injuries is 60% road traffic accidents, 20% falls, 10% work/sport-related injuries, 10% violence.³ According to the international general medical journal *The Lancet*, Eurostat reported that in 24 European Union (EU) countries in 2012, TBI caused 1.4 million hospital discharges, more than 33 thousand fatalities and accounted for 37% of all injury-related deaths.⁴ In Malta in 2012, from the 53 injuries that caused death, 21 were fatalities from TBI.⁵ In the United States, according to the Centres for Disease Control and Prevention (CDC), TBI is a major cause of death/disability.⁶ The CDC reported in 2005, TBI caused 1.8 million emergency room visits and hospitalizations, with nearly 53 thousand deaths.⁷ Lastly, in the state of Ohio in 2005, the year of my accident, traumatic brain injury caused 8,674 hospitalizations, with 2,290 fatalities.⁸

Returning to my own story, I submit simple questions to provide conceptual frameworks which illustrate how massive forces of an automobile collision erased conventional understandings of my essence/identity and reduced me to a collection of cells struggling for survival in an indifferent universe. The first question this article asks is: 'what is reality?' Reality may be seen as matter/energy existing within the space-time continuum. A second question: what is a human being? A human being can be regarded as a discrete mass of biological tissue – a matrix/factory where electrochemical exchanges, interchanges occur. Reality shapes/defines human beings as our biological tissue, awash in nutrient molecules, interacting with external matter, energy and gravity. Most human beings from birth acquire abilities to process reality. Imagine however, processing reality; but at a slower rate; so much slower, society leaves you behind... For weeks, my body existed, but I was separate, without a sense of time.

Longest day of 2005 swept past, with no awareness of self or time, I felt detached and apart. Vague impressions of the outside world: sounds, voices, some comforting/familiar, brought the world closer, then receded. Who am I? What am I? When did this happen? Why was I held captive? In an agitated state, I felt compelled to flee – ripped tubes from throat/body – left bed, only to hit the cold, antiseptic floor, hard. Subdued by staff – tears streaming – fought with every fibre of my being for release; until finally collapsing under the weight of strong hands, exhaustion, sedation; ensnared – entombed in my mind – enmeshed by a strait jacket, unable to escape, pinned to my bed. Few visible scars exist – others indelibly submerged. As memories surface, tears well in my eyes, splash down my face.

As delicate electro-chemical structures of my brain experienced massive damage and disorientation, I existed for months without a sense of time. In the days following my attempt to leave, I complied with treatment. Later, as machines healed me, noises

analysis. Sources examined contain uncertainties in collection methodologies resulting in inconclusive findings. Bob Roozenbeek, Andrew I.R. Maas, David K. Menon, 'Changing Patterns in the Epidemiology of Traumatic Brain Injury', *Nature Reviews Neurology* 9.4 (2013): 231-6; Rita Nguyen *et al.*, 'The International Incidence of Traumatic Brain Injury: A Systematic Review and Meta-Analysis', *The Canadian Journal of Neurological Sciences* 43.6 (2016): 774-85.

³ Hyder, 341.

⁴ Marek Majdan *et al.*, 'Epidemiology of TBI in Europe: Cross-Sectional Analysis', *The Lancet* 1.2 (2016): 76.

⁵ Majdan *et al.*, 80.

⁶ Mark Faul, Likang Xu, Marlena M. Wald and Victor G. Coronado, 'TBI in the United States: Emergency Department Visits, Hospitalizations, and Deaths 2002-2006', Atlanta, GA: Centers for Disease Control and Prevention, National Center for Injury Prevention and Control (2010): 5.

⁷ Faul *et al.*, 42.

⁸ Renee L. Johnson *et al.*, 'State Injury Indicators Report, 4th ed. 2005 Data', *Centers for Disease Control and Prevention* (2018): 90-3.

and terrible odours emanating from the devices summoned me to surface. For months, adult cognition failed me. The operational fulcrum I developed for decision-making became damaged, diminished – reverted. Slowly, steadily I re-engaged my surroundings, but with the cognitive and emotional abilities of a young child. I am informed, my childlike curiosity developed an insatiable hunger for audio/visual stimulation. I would spend hours in bed absorbing the sounds and images of children’s programming on a small television held so close that it touched my nose. Days passed... friends read me children’s books. Others report, I would giggle and bounce my legs up and down in eager anticipation as pages turned. This stimulation helped me greatly as I first re-engaged the world.

Acquisition of spatial relationships, cognitive/psychological/emotional abilities gained in first days and years of life are small, incremental; individuals on neurotypical⁹ life trajectories experience a progression of days where knowledge gained from previous lessons is retained, enhanced, sharpened and cemented. This usual development over time creates the neural pathways that become tools, or lenses with which we learn to recognize, process, and navigate our surroundings. We are equipped at the cellular level to identify and interpret the world we encounter. The brain, encased inside dense bone, receives input from eyes, and sensory organs to process and understand external environments.¹⁰ Most take for granted the time required to navigate disparate elements of reality successfully – to process – make sense of the mélange of ordinary and extraordinary environments in which we find ourselves immersed. I took for granted the neurotypical development I enjoyed prior to my accident; then the disconnection from time and self I experienced, mark the beginning of my new life. As coma/amnesia subsided, somehow, as I filtered back through damaged brain tissues, enough neurons realigned, reactivated and I surfaced fully in late-July 2005. Without a clear understanding of what had occurred, disoriented, overwhelmed by emotion, overjoyed with simply being alive, I reunited with family/friends, then resumed life with my identity profoundly altered.

Brutally cold winter’s night, at home lying in bed, exhausted, I caught a reflection in the mirror, but did not recognize the stranger. Who is he? Looks familiar, but... Suddenly, the sinking realization: face in the mirror was I. Time then dilated for many intense minutes, body convulsed, mind collapsed, tears fell. Like falling from a great height, I shattered on the cold, hard ground of pitiless reality. The episode left me breathless.

My mental and physical decomposition that night was hardly surprising. Only eight months passed since 4:34 pm, Tuesday, May 17, 2005, when I initiated a call, then I failed to yield to an SUV travelling 50 mph and it smashed into me. My injuries were catastrophic. Severe traumatic brain injury with haemorrhaging precipitated states of coma and amnesia, lasting 70 days. In addition, my heart went twice into cardiac arrest, I experienced massive internal bleeding, with lacerations to rectum/liver, multiple hip

⁹ Neurotypical sometimes abbreviated NT, means having a style of neurocognitive functioning that falls within the dominant societal standards of ‘normal’.

¹⁰ Brain neurons or individual cells connect to form processing systems. These cellular networks are responsible for all action, thought, feeling and sensation. Each neuron shares connection with more than a thousand neurons and the adult brain has more than 60 trillion neuronal connections. See, for instance, Joan Stiles, Terry Jernigan, ‘The Basics of Brain Development’, *Neuropsychology Review* 20 (2010): 327.

fractures and developed respiratory MRSA.¹¹ I was discharged from hospital, September 15, 2005. Instead of daily workouts in hospital, I underwent 3 sessions per week of outpatient physical, occupational and speech therapy. By October 2005, I resumed my work as an industrial designer. In January 2006, eight months after the accident, returned to university. All pressures combined to produce the episode. Like using a treadmill that suddenly spins too fast, I fell. Exhausted, brain ceased to process, overwhelmed by fear, shutdown, shuddered. Time sped by so fast – too fast – I could not breathe. I felt like I plummeted towards a bottomless pit looking to swallow me whole; hoped if enough fell, the pool of tears would break my fall; then gently I would float to the surface safe, whole, alive. Twelve and a half years removed as of this writing, searing remembrances of my first temporal dissonance remain. As memories surface, tears well in my eyes, splash down my face.

Pursuing a graduate degree in disability studies (DS) became crucial for my recovery from severe traumatic brain injury. It is doubtful that without exposure to DS I would have realized a way forward so compatible with my new fragile identity. I emerged from coma/amnesia with significant impairments, but with a non-disabled worldview; however, exposure to the socio/cultural/political histories of disabled people, led me to identify as member of a marginalized group. With an awareness of DS scholarship through works by Ervin Goffman, Paul Longmore, Mike Oliver, Ed Roberts, Nancy Eiesland, Simi Linton, Lennard Davis, Rosemary Garland-Thomson, Tom Couser, Simon Burch, Jim Ferris, Kim Nielsen, Ron Amundson, Alison Kafer, David Mitchell and Sharon Snyder, I gained an understanding of the lives of disabled people and their treatment/mistreatment through history. My new, fragile identity internalized DS paradigms and concepts as an organic process. In keeping with the notion of a natural progression for my brain's recovery, if graduate school served as a trellis, I desperately clawed my way up, clung to and spread outward upon as my brain recovered cognitive, psychological and emotional abilities; then DS became the sun, air, minerals and water that nurtured, suffused within me and served as catalyst to construct my new identity as disabled.¹² An example of how I internalized DS paradigms/concepts is demonstrated by the personal connection of lived experiences as severe traumatic brain injury survivor to the foundational scholarship concerning stigma by Erving Goffman. Goffman expounded Greek origins of the word stigma, 'a mark made by a pointed instrument.'¹³ Goffman recalls the custom in ancient Greece to cut or burn into the flesh of slaves, criminals or traitors, marks signifying the individual is socially undesirable.¹⁴ People relegated in this fashion, were considered unusual, morally bad, 'ritually polluted' and avoided, especially in public. Goffman expands on this definition of stigma to describe, '[t]he process by which the reaction of others spoils normal identity':¹⁵

While the stranger is present before us, evidence can arise of his possessing an attribute

¹¹ MRSA is Methicillin-resistant Staphylococcus Aureus, an often-deadly type of staph bacteria that is resistant to several antibiotics; available at <https://www.cdc.gov/mrsa/community/index.html> [accessed 22 June 2018].

¹² Douglas Kidd, 'Disability Studies Influence on a Profoundly Altered Identity', *The Review of Disability Studies: An International Peer Reviewed Journal*, 11.4 (2016): 7.

¹³ s. v. 'stigma', *Oxford English Dictionary* (Oxford: Oxford University Press, 2012).

¹⁴ Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (Englewood Cliffs: Prentice-Hall, 1963), 1.

¹⁵ Goffman, 3.

that makes him different from others in the category of persons for him to be, and of a less desirable kind - in the extreme, a person who is quite thoroughly bad, dangerous, or weak. He is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive; sometimes it is also called a failing, a shortcoming, a handicap.¹⁶

Based on Goffman's description of the mistreatment of people regarded as different, or other, I have little doubt that if I had lived millennia ago, ancient people would have seen my scars, way of walking, how I expressed myself and thought of or called out 'stigma' when I came into view. To many, my scars would have associated me with evil. Likely, I would have fallen victim to shunning, assault or summary execution.

Nevertheless, in the first months of my reorientation to the world, perceptions of others to my physical disfigurements were of no concern. Almost as signs of passage, or evidence of courage or distinctiveness, I would openly display my scars. Carefree as I resumed my life in public, I wore my shirt open at the collar to reveal a nearly two centimetres in diameter scar left by the tracheostomy tube.¹⁷ However, as time passed, I noticed the scar on my throat elicited unwanted stares. For example, a woman made me feel uncomfortable when she stared at my neck as I was waiting on a gurney for my treatment. As I was in a hospital setting, unable to conceal the scar given the limitations of my hospital gown, I was not overly concerned with her stares and did not regard her gaze with alarm.

Nevertheless, all changed as I rode public transit on my way to university one day. As a passenger on the bus, I observed an elderly man with his attention fixed on my scar. Despite nonverbal cues signalling my discomfort to the man's unwanted attentions, his gaze persisted. Some intensely uncomfortable moments later, I closed my shirt. In response to the stigma I experienced, I concealed the scar. It is certain my psyche is now strong enough to withstand the wilful intrusions of others; at the time, only eight months removed from the accident, my cognitive/emotional abilities were greatly diminished and highly sensitive. As demonstrated by the fact that unless I spend a day at the beach, concerns over unwanted attention and my hypersensitivity to stares the tracheostomy tube scar receives persist to the present day, I conceal the scar.

Another stigmatizing scar I have runs nearly the length of my abdomen. I have been informed that the surgical scar developed to address injuries sustained by massive forces generated by the SUV as it collided with me from the left and my body was thrown violently to the right coming hard up against the restraint. The forces caused massive abdominal bleeding and a ruptured spleen. Similarly, to the stigma I encounter with displays of the tracheostomy tube scar, I am sensitive to stares the scar on my abdomen elicits and I choose not display it. As an update and reflection on stigma I continue to experience in 2017, I had plastic surgery to reconstruct my abdominal scar. Nevertheless, while the disfigurement is dramatically decreased, I am still apprehensive over potential stares, so I hide the scar.

However, scars on my abdomen and throat pale in comparison to a dramatic scar on my leg. The scar – which is more than 1 centimetre deep, 5 centimetres wide and 30

¹⁶ Goffman, 2 and 3.

¹⁷ Artificial ventilation, or invasive ventilation using endotracheal or tracheostomy tube is a lifesaving measure in the setting of respiratory failure. See Joe Devasahayam, Troy Whitacre, Tony Oliver, 'Basics and Practical Aspects of Non-invasive Mechanical Ventilation', in *Sleep Issues in Neuromuscular Disorders – A Clinical Guide*, eds Raghav Govindarajan and Pradeep C. Bollu (Cham: Springer, 2018): 117.

centimetres long – is the result of a fasciotomy¹⁸ to treat the compartment syndrome injury¹⁹ to my lower right leg. It is curious that, during warmer months, I am comfortable displaying the scar. I proudly exhibit it as a signifier, or perhaps reminder of extraordinary experiences, which, in turn, feeds my positive self-image.²⁰ However, in sharp contrast to the tracheostomy tube and abdominal scars, I associate no stigma with the scar on my leg. I find the contrasting views regarding embodiment of various scars, and stigma they induce and/or nullify, curious. Upon reflection, I choose to only display scars which project exceptionalism. Alternatively, scars that suggest what I perceive as weakness, stigmatize, cause me shame and urge me to hide from view.

The exchanges described above are similar to Nancy Eiesland's reference to Goffman's 'rituals of degradation.'²¹ Goffman asserts for people with disabilities) they are particularly oppressive.²² Eiesland suggests that, in contrast to the stigma many people with disabilities typically encounter, such as physical avoidance, some non-disabled people are overly fascinated with embodied difference and feel empowered to freely engage people with disabilities in conversation. Many times, this fascination is expressed out of acts of seeming goodwill; yet Eiesland asserts it is inherent in the dominant-submissive paradigm that pervades nondisabled thought, and is an overt attempt to control the lives of people with disabilities.²³ I will explore two interactions with strangers to illustrate Eiesland's observation of 'good-natured intrusions' towards people with disabilities, based solely on perceived difference. In addition, they exemplify how lived experience enhanced my ability to internalize DS concept and paradigms.

One good-natured intrusion, regarding the differences I present, occurred when I was a student walking a university hallway. A young man coming the other direction, stopped as he drew near, looked full of concern, signalled for me to halt and asked without preamble, 'What happened to you?' and 'Are you okay?'. The man did not begin with 'Hello, please ease my concern, how are you?' The fellow student chose to interrupt my progress and said in effect 'I do not really care, but your scars and limp are intriguing, if not threatening, as well as mildly upsetting and that is why I disregard your privacy.' I suppose I should learn to ignore rude intrusions from individuals that treat me this way; but it is difficult for me to speedily process comments from others and I have yet to figure out how to ignore them or politely refuse comment. Instead, and as evidence of a submissive posture, I feel obliged to be polite and answer the concerns of anyone I encounter. Therefore, I proceeded with brief description of events and reasons behind my walk. After this explanation, I assured the man I was not in pain when I walked; in fact, I added, given where I had been, I was proud of and felt very fortunate to have the ability to walk. As a check on reality of the interchange, but for my staggering walk, it is doubtful words would have passed between us.

¹⁸ Fasciotomy is a surgical procedure that cuts away the fascia to relieve tension or pressure. See <https://medical-dictionary.thefreedictionary.com/fasciotomy> [accessed 30 May 2018].

¹⁹ Compartment syndrome occurs when excessive pressure builds up inside an enclosed muscle space in the body. Compartment syndrome usually results from bleeding or swelling after an injury. For more details, see [#1](https://www.webmd.com/pain-management/guide/compartment-syndrome-causes-treatments) [accessed 30 May 2018].

²⁰ Douglas Kidd. 'Collide', *Scar Anthology*, ed. Erin Wood (Little Rock, AR: Et Alia Press, 2015): 84-5.

²¹ Nancy Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability* (Nashville: Abingdon Press, 1994), 92.

²² Eiesland, 92.

²³ Eiesland, 93.

Another ‘good-natured intrusion’ (to make use of Eiesland’s terminology) occurred when an individual perceived the deficiencies in my gait, then felt empowered to share their opinion with me. One day as I proceeded past a woman, without preamble she broke the customary silence with questions: ‘When will you resume physical therapy?’ and ‘Wouldn’t you like to walk normally again?’ As disability studies scholars/activists made me aware and sensitive to the significance and attendant baggage associated with the term ‘normal’, it was all I could do not to express disgust at the individual. In my daily life, it does not occur to me that I walk differently. I am simply moving through the world, living my life and proceeding with activities I desire. Yes, I will admit there are differences when I view myself walking in a mirror. Yes, I agree, I possess a significantly staggering lurch as I walk; but the fact that it took me eighteen months to regain the ability to walk, and in consideration of the wondrous variety of *Homo sapiens* on the planet, I feel my gait is well within the norm and should not provoke comment. However, many only see the exception and choose not to fight the urge to have difference explained. Another prominent way my fragile disabled identity internalized DS concepts and paradigms came once I was introduced to Rosemarie Garland-Thomson’s scholarship. The episodes described above are examples of staring. In her article, ‘Ways of Staring,’ Garland-Thomson’s asserts: ‘[p]art of our enormous communal vocabulary of the eyes, staring is a particularly emphatic way of expressing our response to others.’²⁴ Garland-Thomson contends some non-disabled people feel empowered to express opinions on the difference disabled people present. She suggests staring is an automatic response dictated by perceived necessities of survival and writes: “[w]e are drawn by the unanticipated and the inexplicable in an effort to make sense of experience. We comfortably rely on the predictable, at the same time that we anxiously crave the unpredictable.”²⁵ Furthermore, Garland-Thomson contends natural selection shaped the process of staring over millions of years of human evolution. Those who stare, then seek to engage their subject in conversation are well-meaning, yet, many cannot resist the need to have the unknown explained.²⁶

The following is an example of my lived experience, which illustrates Garland-Thomson’s ideas. One day waiting outside The Metropolitan Museum of Art in New York City, a stranger stared at me several times over the course of a few minutes, then crossed from where she stood and asked if I experienced pain. I said, ‘No, I am not in pain.’ When asked the reason for her question, she replied: ‘The scar running along your leg looks extremely painful.’ I thanked her for the concern, but responded, ‘I am not in pain, just waiting for a friend.’ We proceeded to have a 15-minute discussion. While preoccupied with the momentary arrival of my friend, I felt comfortable enough to explain my accident, scars and brain injury. As I engaged the woman in conversation, she became visibly less anxious about my appearance. Because of her decreased anxiety, soon I felt comfortable relating to her. The woman’s questions about my scars, and appearance originated from her uncertainty over the differences I presented. As staring led to her good-natured intrusion, which seemingly originated out of concern for my comfort and well-being, it is difficult to argue she attempted to oppress me; but rather she could not resist temptation and required exceptions in her environs explained. Confirmation of this notion is demonstrated by the fact that if the woman had not seen my scars, our exchange would have been unlikely.

²⁴ Rosemarie Garland-Thomson, ‘Ways of Staring’, *Journal of Visual Culture* 5.2 (2006): 173.

²⁵ Garland-Thomson, 173 and 174.

²⁶ Garland-Thomson, 174.

The confluence of lived experience and pursuit of a graduate degree in disability studies greatly supported my nascent, fragile identity through natural assimilation of concepts/paradigms stigma, rituals of degradation and staring. However, these are but three of the many DS concepts/paradigms my new, disabled identity absorbed. I now examine further identity development gained from social interactions. Early during my recovery, I confronted significant aphasia, or the inability to produce and/or comprehend speech. Years passed before I regained the ability to speak comfortably outside of family/friends. Opportunities came as I met fellow TBI survivors. With complete acceptance, these understanding people led me to discover community. As interpersonal experiences expanded, I bonded and resonated fully with individuals classified as developmentally or intellectually disabled. When compared with more sophisticated disabled communities, members of this group live on the margin; yet I derive belonging from their presence. The only method one individual has to communicate is by striking himself in the face. If he feels hot or cold, or hungry, or wets himself, he moans, balls his hand into a fist, then hits. The louder he moans, the harder he hits, the more desperate he is for relief. It is difficult to know the borders of our one-time relationship; but it was my duty to attend to his needs, so it gave me great satisfaction to know I could contribute to his momentary peace. While many do not regard his life and speed away on their own missions, his humanity and lessons he teaches, shine.

Turning back to my identification with fellow TBI survivors, I will give a brief description of my own brother's experience after an unfortunate accident. On December 31, 1987 as Richard Kidd attempted to cross a street in Indianapolis, a car without headlights ran through him. Richard acquired additional brain damage when he stopped breathing before rescue personnel arrived. Following his accident, brain damage caused Richard to experience a coma lasting nearly a year. Richard is hemiplegic, with only limited ability to process the world.²⁷

The main lessons Richard teaches regard human fragility, strength, interdependence, neglect and abuse. For example, Richard's life, post-accident, finds him subject to the expressed will of others. Decades of his inability to self-advocate for his health and well-being, nearly cost Richard his life one day. In the 1990s, nursing facility staff dropped Richard and caused his front teeth to shatter when his mouth smashed into the floor. We received the explanation Richard became combative, resisted treatment and his agitation caused the fall. As Richard is hemiplegic, possessing only the ability to yell loudly, he has limited ability to resist. Worse than the fall is that Richard never received follow-up dental care to repair or replace broken teeth. It is impossible to reconcile the fact Richard went decades without dental treatments, but he did. However, when I became a TBI survivor, my identification with and empathy for Richard meant disregard and neglect for his dental care ended. Given bureaucratic delays, what I thought would be routine dental treatment, took months to arrange. What happened next became disastrous for Richard. Due to prolonged lack of dental treatment, the dental surgeon decided to extract all 24 of Richard's teeth in one session. I cannot argue with the dental surgeon's assessment; but Richard's sedentary lifestyle profoundly limited his ability to withstand what for him amounted to trauma. After the extractions were completed, hospital staff wrongly determined Richard stable enough and discharged him back to the nursing facility. Soon after returning to his home, Richard aspirated on

²⁷ Douglas Kidd, 'Disability Embodied: Narrative Exploration of the Lives of Two Brothers Living with Traumatic Brain Injury,' *Narrative Inquiry in Bioethics* 3.3 (2013): 199.

blood produced by the dental extractions. As the nursing facility was ill equipped, staff could not cope with the crisis, so Richard returned to the hospital, then slipped into a coma lasting three weeks. This tragedy confirms Richard's fragility, yet ultimately exhibits his innate strength to withstand decades of extreme neglect and abuse by society.

While Richard's journey is a series of disabling events, my experience is largely one of impairment. In other words, in stark contrast to the abuse and neglect of Richard's experience; my journey is one of recovering and enhancing my physical, cognitive, psychological and emotional abilities to meet challenges by nondisabled society. The critical difference in our realities stems from Richard's inability to self-advocate. Consequently, Richard is unable to resist the actions by others; vulnerable to whim, with his life is subject to chance. Especially early during my recovery, I shared similar circumstances and experiences with Richard. The core of common experiences forged bonds of identification, acceptance, draws me close and leads me to love Richard completely.²⁸ Reflecting on our lives and my journey of self-discovery uses autoethnography and, in this context, poetry provides skills/methods to articulate and thereby position our experiences alongside other disabled people. The confluence of community, the acceptance of new realities I confront and the skill to relate personal experiences compel me to share, seek, and find belonging.

The drive to regain my former self and discover belonging embodies/enminds aspects of Amanda Wicks scholarship. The severe TBI I acquired produced extensive brain damage, which in turn precipitates temporal shifts. These shifts in timing generate profound gaps in my memory. In addition, residual brain damage makes difficult my ability to maintain pace, so I fall out of step, experience social dislocation. In addition, I have become perceived as 'other'. As traumas established a significant void in memory, I struggle to recall and greatly yearn for the one-time integrated progression of my life. It is difficult for me to remember the hours, days and months surrounding the accident. Accordingly, I perceive this gap as an absence, or void that I dimly sense, yet is impossible for me to ignore. In favour of proceeding with more pressing activities of life, I am forced to push past traumas to the margins of my consciousness. Yet, I find myself compelled to reconcile and make sense of past experience. As Wicks suggests, '[t]hose who emerge into trauma's *after* find themselves confronting endless repetitions of their experience.'²⁹ Like many trauma survivors, I endlessly replay the circumstances of my accident in vain hope of recalling memory; yet a wall of brain damage separates me from full understanding, which makes me live with outcomes, forever haunted, grasping after cause. In spite of these difficult to reconcile tensions, ever since returning to consciousness in my hospital bed I am compelled to recover as much as possible. As I moved through occupational, speech, physical therapies and psychological counselling, the greatest recuperative tool in support of my brain's recovery are the writing skills I developed as well as opportunities to share my experiences with audiences. These recuperative efforts provide opportunities to compose narratives that build structures of understanding that nourish my need for intellectual/emotional

²⁸ Douglas Kidd, 'My Brother's Traumatic Brain Injury and Its Effect on Me', in *Barriers and Belonging: Personal Narratives of Disability*, eds Michelle Jarman, Leila Monaghan and Alison Quaggin Harkin, (Philadelphia: Temple University Press, 2017): 87-93.

²⁹ Amanda Wicks, 'No Other Tale to Tell. Trauma and Acts of Forgetting in The Road', *Critical Trauma Studies: Understanding Violence, Conflict and Memory of Everyday Life*, eds Monica J. Casper and Eric Wertheimer (New York and London: New York University Press, 2016): 135.

support and in effect, fill in the missing gaps. The narratives I've composed and shared is precisely the methodology I have used to examine my journey of self-rediscovery. The last aspect of Wicks' scholarship I reference is: '[w]orking through trauma, therefore, ultimately becomes a narrativizing act, because the act of remembering and recounting structures *through* language what has occurred *beyond* language.'³⁰ My journey to (re)discover and (re)claim my shattered identity is supported and bolstered by my efforts to compose articles and present them to audiences. Without these efforts, I am certain my brain would not have recovered, nor would my identity be fully realized. Brain damage affected and interrupted notions I had of my former self. There are times when I feel to have returned fully and recovered, yet in the core of my being I know how vastly different I now process my environs. Like a cloud or veil covering my past, I am forever struggling to reconcile memories of former functioning with new realities.

TBI shattered my identity, or the sense of who I am. The accident reset cognitive/emotional processes developed over the course of my life. Consequently, I am strangely disconnected from the past. Many long-term memories survive, but forces of trauma drastically altered my sense of self. While largely content with life, it is impossible to ignore how the accident completely disrupted my successive development, where first days turned to years, decades passed, I grew older with a continual/seamless awareness of my past-developed plans for the future. The accident caused the course of my life to depart radically from the usual 'straight' time progression most enjoy and experience.

Irrevocably severed from my past, the salient issue of TBI is grief over the loss of my former self. I generally move forward with life, but spend time trying to reclaim former ways of functioning. The drive to return to past methods of processing is innate and parallels neuronormative progression I achieved growing older. Intellectually, I understand I will never be the same person; however, I cannot ignore memories and the urge to regain former problem-solving methods and coping techniques. As my brain now processes, the pace of society at times frightens me. Often, tears occur as I manage the world speeding around me. For this reason, never do I intentionally refer to, nor conceive my brain injury as a past event. Brain damage is always with me. I cannot anticipate how my brain injury will express itself.

The crucible of surviving severe TBI proved fertile ground for the emergence of my neurodivergent³¹ identity. With great assistance from family, peers, medical professionals, I have grown, reconnected with others and largely reintegrated back into the larger world. While seeming to contradict negative descriptions regarding my neurodivergent life, difficult adjustments made on this side of trauma, injury, coma/amnesia, MRSA, awakening, recovering, reintegrating back into society, result with me happier, stronger, in celebration of neurodivergence. My response includes essays, articles, poetry, community service, political expression and presentations to international audiences.

My first opportunity to interact with others, find acceptance and discover community occurred when a friend asked me to participate on a panel discussion at the

³⁰ Wicks, 135.

³¹ Neurodivergent sometimes abbreviated ND, means having a brain that functions in ways that diverge significantly from the dominant societal standards of 'normal'; available at <http://neurocosmopolitanism.com/neurodiversity-some-basic-terms-definitions/> [accessed 21 June 2018].

Society for Disability Studies³² annual meeting in 2014 in Minneapolis. Prior to this experience, I was unaware DS scholars and activists gathered to share community and research. As I never before relayed our story to an audience, apprehension over our story's reception and acceptance made me anxious. This was demonstrated by the poor sleep I experienced for weeks prior to the conference. In addition, concerns over my diminished cognitive skills/abilities led me to feel out of place at such a prestigious and scholarly gathering. Nevertheless, I was surprised and overwhelmed by the warm reception, acceptance and animated response received when I delivered my paper. I recall enthusiastic smiles, bonding and sharing fellowship with fellow conference attendees, which lasted the remainder of our time together.

In the conferences I have participated ever since, I have encountered the same commitment to collegiality and willingness to serve as venues of cultural acceptance for embodied/enminded difference. Since my first conference four years ago, to the most recent facilitated by the University of Malta, I have presented eleven times. The personal growth I gain from these accepting forums, greatly promotes my recovery with opportunities to reduce stigma for severe traumatic brain injury survivors, discover meaning, share community and derive belonging.

Evidenced by my ability to work, service to non-profit boards, lead a support group and partner with a national safety organization, I have recovered a life, largely reclaimed adulthood, and adjusted to neuronormative expectation. Yet, I cannot ignore moments when I dissolve into cognitive misunderstandings and have difficulty processing the pace/breadth of normal/usual interactions. There are times when I find myself isolated, adrift, a stranger. Yet, despite seemingly detrimental and negative aspects described, alternatively, I possess renewed wonder in the world enveloping me, where even the ordinary is extraordinary. My new perception is the template with which I process/decode/decipher reality.

Human beings emerge from and exist within reality. Personal experience illustrates how sensitive the mind/body are as processing tools of reality. Envision the gelatine-like brain defined, ordered, separated by dense bone into compartments of knowing. Consider this working system suddenly, violently shaken so hard, brain damage ensues and total negation of self occurs. For a while, loss dominates. Time passes... Slowly brain tissues heal; they reconstitute, reassemble, restructure at the cellular level. Cognition flickers, self steals back, reclaiming the void. Now, examine one restored human being processing reality in space/time, but with a tendency to slip/disorient; yet throughout my recovery I possess a great desire to realize identity, uncover meaning, and discover belonging.

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Neurodivergența din minte/ din corp. Trăind cu leziuni cerebrale traumatice severe

Rezumat

Acest articol relatează experiența mea ca individ care a suferit leziuni cerebrale traumatice în comparație cu alți supraviețuitori cu leziuni cerebrale traumatice și în contextual persoanelor cu dizabilități care trăiesc în Statele Unite ale Americii și în lume. Această relatare autoetnografică (prin autoetnografie înțelegând metoda de cercetare socială care are scopul de a explora experiențele personale ale cercetătorului) examinează viața unui individ neurodivergent ale cărui funcții ale creierului deviază în mod semnificativ de la normele sociale. Explorez schimbările profunde asupra identității mele și excluderea socială cu care m-am confruntat din momentul în care am suferit leziuni cerebrale traumatice. Alterarea profundă a identității mele afectează abilitatea mea de a procesa informații și de a mă adapta la normele sociale din jurul meu. Pe măsură ce decodez, descifrez și procesez informațiile despre lumea care mă înconjoară, creierul meu declașează și produce episoade de disonanță temporală și pe măsură ce aceste schimbări de temporalitate se petrec, ele au un impact devastator asupra stabilității mele emoționale. În ciuda acestor dificultăți externe, glorific modul în care creierul meu transformă conștientizarea timpului și noua mea identitate ca persoană cu dizabilități. Conectând studii critice ale traumei cu temele pe care articolul le propune, examinez cum trecând prin traumă, comă și amnezie către o nouă viață dominată de o deteriorare a proceselor cognitive și emoționale și de fragilitate fizică au avut rolul important de a îmbogăți exprimarea umanității mele. Articolul demonstrează că aspectele frapante ale noii mele vieți – sensibilitate emoțională și volatilitate – pot fi privite la suprafață ca fiind dăunătoare și nedorite. În ciuda acestei viziuni, aceste calități îmi intensifică consistent identificarea cu alții și empatia față de alții, care, la rândul lor, mă conduc spre a mă exprima artistic, social, cultural și politic și a căuta să mă încadrez în comunitate.