Disability Studies Influence on a Profoundly Altered Identity

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Abstract: This article describes circumstances of my traumatic brain injury, the aftermath, expressions of the brain damage acquired, and current functioning. The article examines the influence exposure to Disability Studies scholarship made to precipitate development of a disabled identity. The article explores advocacy efforts that are my direct response to society.

Keywords: Traumatic Brain Injury, Acquired Disability, Identity

Introduction

On Sunday, May 17, 2015, while in Kailua, Hawai'i preparing to present to the Pacific Rim conference, I celebrated the tenth anniversary of the catastrophic car accident that irrevocably and profoundly altered me and the course of my life. It is difficult to imagine how one could possibly celebrate a catastrophe, because for two and a half months, I experienced states of either coma or amnesia. As I slowly emerged, I regained the ability to process the world around me and expressed joy in reunion with family and friends as I recognized the extraordinary opportunity I had to live. The tremendous upheaval accompanying survival and living in the aftermath of a severe traumatic brain injury (TBI) provides stark contrasts between loss and gain, despair and hope, grief and joy, death and re-birth. Because of the contrasting extremes the accident heightened, I am grateful for the depth of understanding I have regarding the rich experience of simply being alive.

In order to provide context for describing experiences of survival and living with traumatic brain injury in this essay, I provide the following brief description the circumstances of the accident and the injuries I acquired. At 4:34 PM, Tuesday, May 17, 2005, I initiated a cellphone conversation to my brother as we made our separate ways to a golf course. I planned to arrive at the course first, so I am sure the conversation discussed some last minute and trivial details about the outing. I do not recall the accident because a massive SUV (figure 1) travelling about 50 miles per hour slammed into the left side of my small car (figure 2) after I paused briefly at the stop sign before proceeding into the intersection. Everything happened in a blur, leaving me no opportunity to process the event. The driver and sole occupant of the SUV was uninjured. She bore witness to the horrific scene and reported it to rescue personnel. I have been informed that the energies of collision were so terrific my car eventually came to rest in a field dozens of feet from the point of impact.



Figure 1 Photograph of the minor damage to the SUV after the accident



Figure 2 Photograph of Douglas Kidd's car after the accident. One can see the massive damage that was caused by the collision

The consequences of the accident were devastating. Major injuries I sustained included: multiple hip fractures, a crush injury with compartment syndrome (increased pressure in a muscle compartment that can lead to muscle and nerve damage as well as blood flow problems) to my lower right leg, ruptured spleen, bleeding behind my abdomen, lacerations to my liver and rectum, and two cardiac arrests (one at the scene, the other soon after arrival in ER). The most significant injury occurred as my head absorbed enormous energies from the SUV and my brain hemorrhaged severely. Days later while in ICU, a deadly methicillin-resistant staphylococcus aureus (MRSA) infection took hold. I came so close to death from MRSA, and survived, staff at the rehabilitation hospital referred to me as the "miracle man."

I now turn to descriptions of life following my accident. For many days, a tube extended through my mouth and into my lungs, as a machine breathed for me. Weeks passed, turning into a second month, and while far from conscious, I steadily gained a sense of the world around me. As I became more active, a tracheostomy tube was inserted in my throat that breathed for me. In addition, a g-tube became a pathway to deliver food and medicines directly to my stomach. After stabilizing from the initial trauma, I experienced coma for 24 days, followed by amnesia for 45 days. As comas lasting longer than three weeks are rare, I am extremely fortunate to have survived.

A significant injury developed when my lower right leg became crushed against a car panel and burst open. I cannot place a specific memory associated with therapy to treat the wound, but at the edge of awareness, was the incessant sound and unpleasant smell emanating from the device surrounding my right leg. I've no doubt the machine saved my leg, but it forms a hazy memory of the time when I began to surface. It is curious to note, a strong smell like rotting garbage, and an incessant humming noise, stimulated my initial reconnection to the world and welcomed me back to life.

What I am sure was a gradual accumulation of days where I increasingly became more aware of my surroundings, looking back seems like a switch turned and I surfaced fully one day in late July, 2005. About three months after the accident, I initiated conversation with a nursing facility aide. For reasons I could not explain, I had the vague impression I did not like him much. He suggested my dislike for him likely occurred as I steadily regained consciousness, frequently fighting against him. He explained, with no awareness of what had happened to me, or my current circumstances, that I became disoriented, agitated, and actively began to resist treatment. One day, I managed to rip the trach tube from my throat and tumbled out of bed. Following this incident, for my own protection, restraints limiting my mobility were used. As my discharge from hospital approached, I arranged to meet the man. I wanted to thank him for helping me when I needed it and apologize for my behavior. He welcomed my appreciation of his efforts, assured me there was no need to apologize to him, and we parted as friends.

I have no distinct memories of the states of coma and amnesia I experienced for two and a half months. Occasionally, images form of lying in a hospital bed, tubes keeping me alive, restraints in place, with me fighting desperately against them. These imaginings often produce a flood of raw emotion. I am truly okay with the crying episodes that frequently occur; because I recognize tears as the natural expression of the brain damage I acquired. At times, I do not have to recall the past to break into tears. A beautiful melody, or a touching scene from entertainment or a book, or expressions of love and regard exchanged between people, overwhelm the logical and rational parts of my mind and I dissolve in tears. Often, sharing among friends becomes too much to process without my mind blanking and a flood of raw emotion ensuing. When I reflect, strong emotional responses occur when I witness or contemplate expressions of human warmth and kindness, along with prospects and efforts made in support a hopeful future. I have come to treasure tears for their ability to place the experience of being alive into stark relief. My emotional delicateness is an outcome of the brain damage I acquired, defines my reality, and forms a significant aspect of my new identity.

Before providing examples of my emotional delicateness, I turn to Disability Studies scholarship to describe my experience of acquiring multiple disabilities. Disability Studies has helped me make sense of how this event drastically altered my identity, my sense of self, and largely describes my life. Alison Kafer (2013) provides a theoretical framework to understand aspects of my experience. In her book *Feminist, Crip, Queer*, Kafer suggests disability renders time queer (p. 34). Applying this notion to my circumstances, the magnitude of brain damage caused me to experience extended time dilation while in states of either coma or amnesia. As my brain absorbed enormous energies from the SUV, weighing more than six thousand pounds and travelling 50 miles per hour when it slammed into me, the delicate electro-chemical structures of the neurons of my brain experienced massive damage, disorientation, and I existed for months

without a sense of passage of time (Chevrolet, n.d.). As the trauma, coma, and amnesia subsided, my new identity became profoundly altered. Somehow, as I "filtered" back through the damaged brain tissues, enough neurons realigned, and finally I surfaced. While my new identity's awareness of time has largely returned to pre-accident levels of acuity; the glaring exceptions noted below, provide examples of the disorientation my brain at times experiences. In addition, my experience confirms and offers as example Kafer's suggestion (2013, p. 34):

"Not only might they cause time to slow, or to be experienced in quick bursts, they can lead to feelings of asynchrony or temporal dissonance; depression, and mania are often experienced through time shifts, and people with various impairments move or think at a slower (or faster) pace than culturally expected."

As confirmation of Kafer's suggestion, at times I experience symptoms of Major Depression and mania, because as I attempt to process my surroundings with drastically altered cognitive, emotional/psychological abilities, my brain moves at a slower speed, out of step with other people.

An example of my previously referenced emotional fragility, which reflects Kafer's discussion of asynchrony or temporal dissonance impaired individuals experience, occurred shortly after I returned home from the hospital. It was at the end of a long day in late-January 2006. As I lay in bed, my mind raced and I caught my reflection in a mirror. Suddenly, it felt as if the bottom dropped out of my life and I hovered above the yawning abyss of my unknown future. This experience terrified me greatly. My only response was to burst into tears, and my entire body shook for 15 minutes. As I reflect, this was an example of my brain attempting to process the multiple aspects of my newly recovered life, emerging identity, and my mind simply quailed. Clearly, I had difficulty processing the pace of my new life. This is hardly surprising considering the severity of my injuries. It had been only four months since I left the hospital, eight months since the accident, and I returned to work fulltime while attending college part time.

Illustrating Kafer's idea that impaired individuals experience asynchrony or temporal dissonance, another example of my emotional instability occurred when I attended a concert at Millennium Park in Chicago in late-August 2008. It was a perfect summer night and I lay on the ground looking up at the stunning skyline of Chicago. As I marveled at the beautiful sky, and amazing latticework structure that seems to float in air above the pavilion lawn, I found myself thinking about all that I experienced since the accident and became unable to contain the flood of emotion these thoughts produced. I felt I was somehow disconnected from my body, helpless to control my tears for about fifteen minutes. I do not accept "out of body" experiences; but I distinctly recall thinking while in that emotional state that it was someone else who cried uncontrollably, and as much as my heart ached for him, I could do nothing to stop his tears. It occurs to me, the emotional breakdown I experienced that night was in part due to a sudden remembrance of all the pain I experienced during and following the accident, and yet, at the same time, I was overwhelmed with joy because, against tremendous odds, I had the opportunity to live my life again. I made it through an incredible ordeal with a chance to share in all the joys and sorrows life can bring.

This happened the Saturday before I would begin working as a graduate assistant for the Disability Studies program at the University of Toledo, and so it was hardly surprising that I experienced such an emotional outburst. Prior to Chicago, given the severity of my brain injury, I felt insecure about my ability to perform graduate level work. As I reflect, a significant feature of my traumatic brain injury is uncertainty over my ability to cope with life's pressures. That night foreshadowed later difficulties I would experience as a graduate student.

While I am largely content and happy with my life, it is impossible for me to ignore how the accident completely disrupted the course of my successive development, where first days of life became years, decades passed, and I grew older with continual awareness of my past, present, and I developed a plan for my future. Kafer suggests impaired individuals encounter disconnects in the timings of their lives when she writes, "These shifts in timing and pacing can of necessity and by design lead to departures from "straight" time, whether straight time means a firm delineation between past/present/future, or an expectation of a linear development from dependent childhood to independent reproductive adulthood (p. 34). As mentioned the course of my life since the accident largely follows the straight time path Kafer suggests. However, the two major episodes referenced above - at home shortly after hospital discharge and Millennium Park in Chicago - as well as other minor episodes not described here, clearly indicate instances where the brain damage I live with compels drastically altered experiences of reality which had never occurred before the accident.

An incident that occurred about two and a half years after my accident provides a window into my cognitive functioning, emotional sensitivity, and provides an example of Kafer's discussion of impaired individuals' thinking as slower than culturally expected. I mention this as an example of formerly impaired cognitive ability because now that I have recovered enough, this would not likely occur. At the time, I believed everyone, even strangers, conducted their affairs honestly and never did anything to threaten or harm others. General belief in the goodness of people remains problematic for me; but as I returned home, a stranger caught my attention and requested assistance. The man said his car had run out of gas some distance away leaving his wife and two children stranded in a city they did not know. He asked me if I had money for gas. Truly, I did not have enough money on me to give him, but volunteered to take him to an ATM. Fortunately, the ATM was some distance away. This gave me time to examine the man closely where I read his nonverbal cues: he seemed nervous, detected poor hygiene, saw his tattered clothing, and through conversation observed, he made several contradictory statements. Soon, I became alarmed as I realized I planned to take the man to an ATM where he might subsequently rob me. A few weeks prior, I learned in terms of per capita income, the area where I live is statistically among the poorest in the United States. Weighing all these factors, as soon as I could, I found a shopping center crowded with people, stopped the car, opened the door, and exited. I now felt comfortable he would not attack with others there to potentially intervene, so I instructed him to get out of my car. After arriving home, I shuddered, thought what might have occurred, then collapsed in tears.

In addition to the issues of emotional instability and cognitive impairment described above, the traumatic brain injury I experienced completely shattered my identity, or sense of who I am. This may seem an unlikely statement, and possibly difficult to accept because my long-term memories are largely intact. To all appearances, I recovered my life and I seem "normal."

Nevertheless, the brain damage I experience greatly affects my ability to make physical, cognitive, and emotional adjustments to society. Especially during early days of recovery, I had tremendous difficulty with brain processing speed, concentration, speech aphasia, emotional stability, and an experience common for many traumatic brain injury survivors - grief over the loss of my former self. Rudi Coetzer suggests traumatic brain injury survivors have trouble with emotional adjustments as they attempt to reintegrate back into society. Coetzewr explains survivors experience dislocation from society by having impaired self-awareness, loss, grief, and finding meaning in their lives (ix, x, 12). Living with limited self-awareness, loss, grief, and finding meaning in my life are the principal dislocations to my identity that I experience. The quality of grief accompanying a severe traumatic brain injury is the salient issue I've encountered in my recovery and is difficult to describe. In my case, use of the word "grief" is apt because a central part of my identity greatly desires to function as I once did, but in reality, I never will. This is difficult to accept. Accordingly, often I experience great sadness and mourn for the person I used to be. This seemingly contradicts statements made about accepting impairment, and approaching life with a positive outlook, and I am grateful for the tension grief adds to my life; but I am largely able to disconnect from mourning, and the dominant part of me strongly insists on survival.

As mentioned previously, the traumatic brain injury I experienced completely shattered my identity. I reference Dominick LaCapra's (2006) scholarship to expand on this idea. LaCapra says (p. 236):

"With respect to identity-formation, one should make special mention of the founding trauma in the life of individuals and groups. The founding trauma is the actual or imagined event (or series of extreme or limit events) that poses in accentuated fashion the very question of identity yet may paradoxically become the very basis of an individual or collective identity. ...it (founding trauma) may also become the basis of a new identity."

As I reflect on these words, while my new identity is largely established, the brain damage forced me to lose the sense of who I was and more importantly, who I am. I lost the common filters and/or safeguards developed to navigate relationships, which I learned as I grew older. This causes me to experience significant social disconnections and difficulties. However, I successfully maneuvered around the damaged brain tissues, or rather created new pathways through to compensate. It is an everyday and ongoing process of recovery to claim my new identity.

Before examining my decision to pursue a graduate degree in Disability Studies while living with severe traumatic brain injury, I need to describe a relationship critical to my acceptance of disabled people. On December 31, 1987, my brother Richard as a pedestrian attempted to cross a street in Indianapolis when a hit and run driver without headlights collided with him. Richard experienced multiple compound fractures to both legs and a severe closed-head traumatic brain injury. Additional complications occurred as Richard stopped breathing for an unknown period before rescue personnel arrived. As a result of the collision, Richard acquired massive brain damage, resulting in a coma lasting approximately eleven months. Due to the extent of brain damage, Richard cannot process the passing days, is hemiplegic, and is only able

to control the right side of his body. Richard does speak and possesses many long-term memories, but requires prompting.

I need to reference Richard's experience here because before my accident I was nondisabled, regarded him as other, distanced myself from his needs, and excluded him from my life. Richard became a doorway to loss and pain. In spite of the fact he used to live within ten miles, I would go months, sometimes years without seeing Richard. Now, rarely a week passes, but that I don't see Richard, and I continually look to his care. Where I largely encounter impairment, society disables Richard. However, as my recovery progressed, and I gained independence and mobility, I often visited Richard. Richard became the touchstone of my identity as a disabled person, his life anchors mine, as someone I love dearly, and as a fellow traumatic brain injury survivor his experience resonates deeply. I did not realize this at the time, but unconditional acceptance of Richard signaled the foundation of my new identity as a disabled person.

Since emerging from the coma and amnesia at the rehabilitation hospital, I've been driven to recover as much of my life as quickly as possible. I returned to work fulltime, as an aluminum die cast designer and part time student, within eight months of my accident. Then, in favor of completing my degree, I abandoned a decades-long career I'd worked in or towards since aged fourteen. As I actively sought employment for more than a year following graduation from college I came up against a startling statistic: unemployment levels for disabled people are more than 60%. However, employment opportunities improve for those who are able to achieve a Master's degree. In order to increase my opportunities for employment, as well as promote recovery of my brain, in early 2008 I applied for the Master of Liberal Studies with a concentration in Disability Studies degree program at the University of Toledo. Additionally, I applied for the program's Graduate Assistant position. Later that summer, I learned not only had I been accepted to graduate school, but would begin fall 2008 semester as a Graduate Assistant. These two events became pivotal to my continued recovery from severe traumatic brain injury and precipitated development of my disabled identity.

Prior to graduate school, I could not anticipate how the experience would profoundly alter my consciousness. Exposure to Disability Studies scholarship as I understood it through the works of Erving Goffman, Paul Longmore, Ed Roberts, Simi Linton, Mike Oliver, Lennard Davis, Rosemarie Garland Thomson, Jim Ferris, Thomas Couser, Susan Burch, Kim Nielsen, Ron Amundson, Rachel Adams, James Wilson and Cynthia Lewiecki-Wilson, Sharon Snyder and David Mitchell, provided me with a depth of understanding of the lives of disabled people and their treatment/mistreatment by society through history. As my new identity became exposed to ideas presented by the scholars above, I internalized Disability Studies paradigms and concepts much like an organic process. In keeping with the idea of a natural progression for my brain's recovery, if graduate school served as the trellis I desperately clawed my way up, clung to, and spread outward upon as my brain recovered cognitive, psychological, and emotional abilities; then Disability Studies became the sun, air, minerals, and water that nurtured, suffused within me, and served as catalyst to construct my new disabled identity.

One illustration of this idea is that my understanding, sensitivity, and response to stigma occurred gradually as I re-engaged with society. For example, during the first few months after the accident, I did not try to hide the physical disfigurements I possess. However, as time passed, I developed a very different response to the feedback my scars provoked. On the one hand, there is a dramatic scar on my lower right leg more than a foot long, which tapers to an inch wide and nearly a half inch deep. Yet, I am not sensitive to displaying the scar; in fact, I often wear shorts and choose to show this scar. I do this because the scar signals to myself, and others that I have come through extraordinary circumstances, which in turn feeds my positive self-image. Alternatively, there is the scar on my neck made to accommodate the tracheostomy tube. In the first months after I surfaced, I did not care how others perceived this scar and did not bother to conceal it. However, one day at a physical therapy session, a man stared at the scar continually for more than thirty minutes. My fragile identity did not permit me to disregard or challenge him, but I became extremely uncomfortable because he stared for a prolonged time at the scar on my neck. I concealed the scar as soon as I could, and unless it's a rare day spent at a beach or pool, the scar remains hidden. I offer this explanation for my very different response to these scars. The scar on my leg is about one hundred times larger than the scar in my throat, so clearly, size is not the stigmatizing issue; but the scar left by the trach tube is a near-facial disfigurement, and I am overly sensitive to the stares this scar evokes.

Feelings of inferiority surface and I desire to hide from the gaze of others when I reflect on negative feedback from others regarding some of my physical disfigurements. This is an example of how my fragile self-image and uncertain identity attempts to manage my surroundings. Stigma permeates our culture, and prior to graduate school I possessed only a general understanding of the term; but knowledge gained as I absorbed Disability Studies scholarship, especially Erving Goffman's seminal work, provided me with the theoretical framework to fully understand the concept I internalized when my physical disfigurements produced the social response (Goffman, 3).

Further illustrating my emerging disabled identities' development as a natural reaction to Disability Studies scholarship are evidenced by sensitivities I developed towards limiting environmental structures and the advocacy efforts I have made in response. For example, on my way into work as a graduate assistant one day, I observed a new construction site at the university. The most striking aspect of the site was placement of large waste containers squarely on the few accessible parking spaces in the area. As the containers stood there for weeks, evidently without report from others, I documented their placement one weekend, then sent the images to the appropriate university office. As soon at the facilities manager received the photos, the waste containers were removed.

Another advocacy outcome developed in response to sensitivities I developed as a disabled person. As I used public transit to travel to the university one day, I observed several deficiencies at the suburban bus stop platform located adjacent to the area's major shopping center. As member of a city/county disability commission, I initiated efforts that led the mall to improve its accessibility. My awareness of advocacy efforts learned in Disability Studies courses, combined with personal experiences of impairment, led me to seek improved access to the mall for the community. It is not necessary to be a traumatic brain injury survivor, and serve disability-related organizations seeking to improve structures that limit individuals; but it took

me eighteen months to regain the ability walk again. My new identity as a disabled person finds me acutely aware of structural barriers, and I do not hesitate to seek improvement of restrictive environments and facilities.

In my former work as a Peer Support Specialist, and current employment as a Qualified Health Home Specialist for a large healthcare provider committed to supporting and empowering individuals, I daily affirm my disabled identity as a traumatic brain injury survivor, and validate knowledge I gained as I pursued a graduate degree in Disability Studies. While the job description to work as a peer supporter with individuals living with symptoms of Severe Persistent Mental Issues (SPMI) does not require a master's degree, it does demand lived experience of significant emotional, cognitive, or psychological impairment. In addition, the work I performed as a graduate student in Disability Studies provided a good conceptual framework for my complete acceptance of the individuals I assist. These factors support me well as I provide a crucial point of connection for individuals seeking treatment and directly support their ability to live and thrive in the community. A significant example of the strength of peer relationships is evidenced by the fact an individual withdrew from psychiatric treatment. Several months passed and the individual reached out specifically for my help as they looked to resume treatment. My former work as a peer supportor is the culmination of many years of effort of recovery and would not be possible without complete acceptance of my new disabled identity.

Looking back, my newly formed and fragile identity came under tremendous stress as I attempted to meet the demands of being a graduate assistant and a student with slowed processing speed issues caused by the traumatic brain injury. Preparing for class, completing assignments, and my obligations as a GA compelled me to work seven days a week and fourteen-hour days were routine. I soon exhibited several symptoms of major depression, i.e. loss of appetite, sleep difficulties, continual sadness and crying, as well as diminished self-worth. However, given my ability and desire to survive, I never considered self-harm. The main reason for this is that even while experiencing despair; I said to myself, "Douglas, while the severe traumatic brain injury you acquired is an enormous challenge, you have requisite skills, you innately know how to survive, so take heart, be patient, you will succeed." In addition to these daily positive self-affirmations, shortly after graduate school began in September 2008, I attended weekly meetings with a counselor. These therapy sessions helped me immensely learn how to focus on the work, believe in myself, and take time to relax and enjoy the college experience. While continually reminding myself of these ideas, the first year of graduate school was extremely difficult. I informed instructors about my injury, registered with the university's Office of Accessibility and received accommodations. With these supports in place I survived my first two semesters. However, given my limitations, the graduate assistantship ended with the school year. Nevertheless, with great effort over the course of the next semesters, I developed a reading strategy that assisted me with course requirements; and by working with a psychological counselor every week to maintain emotional stability. I knew I would eventually succeed. It took me four years to complete my graduate degree; but in the end, the experience shaped my new identity by providing avenues for me to reconnect with society as a disabled person.

From some of the negative aspects of surviving and living with a severe traumatic brain injury described above, it is difficult to imagine how I could possibly regard my experiences as a net positive. However, as I experienced great emotional turmoil and upset while I pursued the graduate degree; it was difficult for me to recognize how my daily efforts greatly enhanced the recovery of brain tissues and restructured damaged neural pathways that hemorrhaged in the accident. It is impossible for me to ignore the tremendous cognitive growth and emotional stability I experienced and now enjoy because of my efforts in graduate school. The brain damage caused my identity to experience such tremendous and dramatic change that the effect of accident continues to the present day. So much so that I never intentionally refer or conceive of the injury to my brain in the past tense. Principally because the daily complexity required to process, and then interact with the world compels my brain to respond. This unending process improves the flexibility of my brain, which ultimately strengthens me.

Accompanying this cognitive growth, I realize the benefits of my decision to pursue a graduate degree in Disability Studies daily. Chief among the gifts: very significant enhancement of cognitive abilities, which in turn bolsters my emotional stability; improvement of my expression of humanity for others by learning the history of disabled people; recognition of social and environmental barriers that limit individuals and thereby society; development of marketable skills in order to ultimately survive; Disability Studies concepts and paradigms became lenses through which I now interpret and interact with society; and most significantly, personal acceptance of my identity as a disabled person. These elements combine every day as I process and interact with my surroundings, leading me to advocate the improvement of the lives of individuals, and to alter society from the empowered organizations I now serve. My life since the accident follows the pattern of the quest narrative Arthur Frank describes (1995, p. 115). As evidenced by the positive aspects of survival and living with multiple disabilities, combined with the awareness gained as I pursued a graduate degree in Disability Studies, made available requisite skills to recognize, interact, and respond to the world I encounter.

In summation, the crucible that graduate school became for me, in the end proved fertile ground for my new disabled identity to find foothold, grow, reconnect with others, reintegrate back into the larger world, and continues to drive my efforts to contribute to creation of inclusive societies. In closing, this statement seems to contradict previous negative descriptions I have made regarding my life following the severe traumatic brain injury I acquired; but the difficult adjustments I've made on this side of accident, trauma, injury, coma, MRSA, amnesia, awakening, recovering, and integrating back into society, result with me happier, stronger, and a better person, grateful for lessons learned about this precious life.

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