

Reconciling Mystical Experience with Concept of the Self: The Poetry of an Individual with Right Temporal Lobectomy

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Abstract

It is recognized within rehabilitation that the right hemisphere association area integrates sensations and mental experiences into a sense of self, and that injury to this region leads to “disorders of the self.” However, there is inadequate understanding of the experiential nature of a reduced sense of self for individuals with such injuries, and particularly of positive experiences. In fact, many individuals with such conditions report mystical experiences associated with a sense of undifferentiated unity or unitary consciousness. To date there has been little discussion of the positive experiential nature of a reduced sense of self for rehabilitation patients, in part due to the scientific focus of medical treatment on impairments, as well as to the limited use of the humanities within rehabilitation.

This article presents the case study of a 47-year-old individual with a right temporal lobectomy at age 22 due to increasing seizures related to an arteriovenous malformation, who wrote poetry over the past 30 years to express her positive mystical experiences. This

article presents her medical history, a narrative summary of her negative and positive seizure- and surgery-related experiences, and several poems about her experiences. Recognition of positive aspects to disorders has broad implications for rehabilitation of patients across medical fields, but we argue the importance is exceptional for cases involving mystical experience. Not only do these patients often feel an insoluble conflict between a positive experience and a health struggle, but these experiences are known for their difficulty to convey. This case study demonstrates the substantial rehabilitation benefits that may be realized through increased reliance on the humanities for expression to reconcile the science of a medical diagnosis with a personal experience.

Introduction

There is increased recognition within rehabilitation that individuals with dysfunction of the right hemisphere experience “disorders of the self.”^{1,2} Such disorders include anosognosia (the inability to recognize one’s own impairments),² alexithymia (the inability to recognize/identify one’s own emotions),³

and mirror misidentification disorder (MMD; the inability to recognize one's own reflection in a mirror).⁴ However, such disorders have been hard to define, and therefore treat, given weaknesses in accurately conceptualizing the nature of the 'self.' Throughout history, the self has been depicted generally as a permanent, unchanging entity.⁵ Many individuals think of the self in terms of a 'soul,' or as a 'self-concept' or 'self-identity,' which may be determined by many factors including genetics, environment, and social relationships. Recent research indicates that the self is best conceptualized and understood as a *neuropsychological process* that occurs within the right hemisphere association area that integrates sensations (ie, sight, sound, touch, smell, taste, positioning) and mental experiences (eg, thoughts, emotions) into a "sense of self."⁶ This process, the making or enacting of the self, cannot be differentiated from the entity of the self as traditionally defined.⁷ This subtle, though important, realization forms the foundation for the personal narrative that follows: the making, the *describing*, of the self or a disorder thereof, also cannot be differentiated from the self.

It has been suggested that the experiential nature of "sense of self" may be best understood in terms of a sense of ownership or "mineness."^{8,9} Conceptualizing "disorders of the self" in this manner helps to explain the dis-integrative experience of anosognosia (not my impairment), alexithymia (not my emotion), and MMD (not my reflection). Other neurologic and psychiatric conditions may be similarly conceptualized as right hemisphere-based disorders of dis-integration of the self, including schizophrenia (ie, not my thought)¹⁰ and depersonalization disorder (not my experience).¹¹ So-called "disorders" of the self are typically described using negative terminologies, such as "not my/mine." Therefore, such experiences have been difficult for rehabilitation professionals to understand and thereby

to treat, as well as for the individuals with the conditions to explain, because without a sense of self, there is no perspective from which to relate the experiences. For example, individuals have been noted to describe their experiences as if removed from them, using statements such as "it is as if..." "it seems like..." and "others tell me that..."^{11, 12} Several autobiographies (eg, *Brain on Fire*,¹³ *My Stroke of Insight*¹⁴) and novels (eg, *Left Neglected*¹⁵) have attempted to describe the experience of these right-hemisphere disorders, although like the medical literature, they have focused on their negative aspects, consistent with medical models of health that focus on disease, disorders, and impairments.

Our first purpose in this article is to describe the positive nature of a patient's experiences of right-hemisphere "selflessness" alongside the traditional "disorder-related" symptoms and difficulties. We present the case study of an individual with a right temporal lobectomy secondary to an arteriovenous malformation (AVM) and related seizures, who has experienced transcendent, mystical experiences since childhood. She gives examples of her poetry that describe her experiences of a reduced sense of self and connection with the infinite, consistent with traditional religious convictions of connection to a greater entity and perhaps most notably to Hindu concepts of individual and cosmic selves.

Our second purpose in this article—co-authored by a patient who is a scientist and poet, and by a neuroscientist and clinician—is to explicitly describe a case study both in terms of the sciences and humanities. A dichotomy between these fields has been recognized for decades;¹⁶ it presents an obstacle to healing that otherwise might be found through rehabilitation that integrates both fields. We hope this case study will serve as one model of open dialogue

between the sciences and humanities, through the use of narrative and poetry, to achieve rehabilitation for the unique set of disorders that involves questions of the self, and especially positive mystical experiences.

The Humanities and Positive Experiences of Selflessness

It is increasingly recognized that many individuals with reduced/inhibited functioning of the right hemisphere association area also report having positive experiences related to a reduced sense of self. For some individuals, this appears to allow for the experience of spiritual connection beyond the self, which is typically described in terms of transcendent, mystical, or ecstatic experiences. For example, many renowned individuals with brain conditions, including epilepsy, have described their transcendent experiences in terms of a reduced sense of self and associated experience of a unitary consciousness (eg, Karen Armstrong, Fyodor Dostoyevsky; Table). These epilepsy-related transcendent experiences are similar to the “normal” transcendent experiences reported by mystics throughout history,¹⁷ which have also been shown to be related to reduced right-hemisphere physiological activity.¹⁸⁻²⁰

Unfortunately, with the focus of rehabilitation on remediation of impairments, there has been little attention paid to the positive experiences of individuals with “disorders of the self.” In addition, there has been limited recognition that some individuals even use these positive experiences to cope with their medical conditions and to expand their consciousness. In fact, many individuals with such conditions resist treatment for fear of losing access to transcendent states.³²

Given the difficulties inherent in describing selfless

experiences, many individuals with and without neurological disorders have turned to the humanities (eg, poetry, art, music) to help them understand and relate their experiences.²⁸ In cases involving experiences of selflessness or unitary consciousness, these expressions are especially important because such individuals often feel strongly compelled to tell others about their experiences, yet find difficulty in identifying the means to do so (Table). There is a whole vocabulary for impairments, but few words for describing positive transcendent experiences without adopting religious, supernatural, or delusional undertones. Arguably, rehabilitation professionals need to be better informed of the positive nature of such right-hemisphere “disorders,” and particularly, of how they can assist individuals with such conditions by providing therapies within the humanities to help them better cope, understand, or even thrive with their conditions.

A Medical History

The first author (MS) was noted to have a normal development and no significant medical history other than complex partial seizures that developed at approximately age 9, and involved approximately 1 to 4 seizures per month, including both auras and *déjà vu* experiences. She had one generalized tonic/clonic seizure at age 22, and had limited success in controlling the seizures with medications. An MRI indicated a right temporal lobe complete vascular malformation; an EEG indicated sharp wave discharges localized to the region of the malformation. Her neurological workup was normal. She underwent a bi-temporal craniotomy and resection of the cryptovascular mass, but required a subsequent right anterior temporal lobectomy that included the malformation, anteriolateral temporal lobe, temporal pole, region of the amygdala, and anterior portion of the

hippocampus. Her recovery was without complications.

A neuropsychological evaluation immediately prior to her surgery indicated that she occasionally experienced an “altered reality” that was associated with “a large knowledge that wasn’t there before.” She further indicated that she experienced “a weird perception of objects around me; they’re distorted, reality seems different.” Neuropsychological testing indicated that she was of relatively strong verbal intellectual abilities with relative weaknesses in visual-spatial intelligence (ie, a 17-point difference between her Verbal and Performance IQ scores). Variability in memory scores was evident, and particularly in visual memory, which ranged from high to below average. Other abilities assessed were generally within normal limits.

Educationally, MS earned a doctoral degree in botany, and was noted to be a good student throughout her education, earning the title of class valedictorian in high school. She is employed full-time as a vegetation ecologist and has been married for 24 years. Her current health is generally good.

Clinical Seizure Experiences

Because my co-author and I aim to demonstrate that expressive writing is essential to convey personal experience, we note here that precision in the language of self-perspective is essential. Therefore, there is a need to now shift to writing in the first person to describe my (MS’s) perspective.

This mode is also needed to convey that the positive side of my experiences has been immeasurably greater than the negative side that was so emphasized during the course of my medical treatment. Around the age of 9, I began to have what I felt to be a secret sight, auras,

or visions as I called them, because I sensed them mostly by sight. As an outdoorsy child, I marveled at nature, but also perceived a powerful clarity, some underlying reality that I thought to be religion, to be God. I felt baffled that this sight was believed to dwell within the confines of churches and stories of the past, but assumed that adults knew something that I did not and that it would all be clear someday. Around age 13, I started to have lapses of consciousness, small black-outs. At the time, I did not associate the black-outs with my visions, but rather assumed I was having unrelated fainting spells. In church once, they gave me smelling salts after blacking out. In high school, my friends asked, “Are you all right? You seemed to fade away for a few moments? You just asked me where you were.”

Diagnoses and Surgery. I began attending Reed College in 1991, after which my black-outs became frequent, often more than once daily, and I became familiar with the auras that preceded them. Coursework became difficult, because my body required sleep after the exhaustion of each episode, and I found corners of the library throughout the day for this purpose. I remember the first visit to the doctor, when he pointed to my brain’s image on the wall and said, “I don’t see anything unusual. Wait, what’s this?” I remember him speaking the word “epilepsy,” and over the weeks and months to come, being labeled with many words that started with “dis”: diseased, disabled, disordered. At this time, I realized the conundrum: that a bad side was present in my experiences—especially if they were to worsen—and yet there was this beauty that I could not imagine parting with. Contrary to any negative labels, my experiences made me feel exceptionally *at ease*, *enabled*, and quite *in order*: indeed, clairvoyant. I became acutely aware that I was living in the presence of the most beautiful and perfect unspoken word, which was oddly waged in a battle

against itself.

I was prescribed several medications to control the seizures, but they only increased in frequency. In December 1994 during an evening college seminar, it was determined I had had a tonic/clonic seizure, based on the way I had fallen onto the student next to me and wet my pants, later to awake at my apartment with a sore body, followed by 24 hours with vertigo and vomiting. My roommate called an ambulance that day and I missed my mid-term exams, but then recovered sufficiently to finish my final college semester, although I blacked out walking into the graduation ceremony. It was clear then that my career prospects would be limited by this condition; within a matter of months, I decided to go through with the surgery as described above.

Finding a Way to Heal. In the short time between deciding on surgery and its arrival, I committed my mind to finding a way to heal, which I knew would be through the positive side of my visions; I want to emphasize that I had *no doubt* in this. I pondered who I was and who I might be after surgery. Out of necessity for survival, I realized that I could push my ‘self’ out to nothing, dispersed into everything, through my experiences. Moreover, I learned this did not always happen on its own, but that the pathway could be learned, and could be practiced and perfected. The unity that had once just fallen upon me, I could seek out, by seeing its all-accepting nature and allowing myself to be enfolded by and attached to it. This feeling gave me great comfort because I knew that no matter what surgery brought, even death, I would still be me. At the time, I did not use the word *selflessness* to describe this experience, but decades later now recognize it to be just that.

Selfless Experiences

‘Selflessness’ is a convenient starting point to describe these experiences. This word conveys a gap, an emptiness, with a potential to be filled in either a detrimental or beneficial manner. My experiences fell into the latter category, one in which increased ‘selflessness’ provided an opening to experience a greater unitary consciousness. Had that gap not been present and then filled, I may have otherwise perceived a loss. Although framing my experiences this way helps to convey them, I cannot describe any transition to a “losing” of the self, such as described by Roberts.²⁶ Perhaps that is because my experiences began at a young age and I therefore do not have a time before them with which to compare. Rather, the immediate sense that I felt was a different word for ‘selflessness,’ its complement or inverse, if you will: *unity*. In words I recall thinking in my youth, I saw a flash of something solid, a connection, a feeling of what was real, of everything together at peace. An unrequested yet omnipresent and pure quality in my field of view.

As a teenager I realized that peers or adults did not seem to intuit this same thing, but reading transcendentalists in school, I knew I was not alone in these insights. I excelled academically and my teachers encouraged me to write creatively.

The poem “Teenage Revelation” was my first written attempt at grappling with my experiences.

Teenage Revelation

I am plagued by obvious
self-evident lectures
pastoral, green landscapes
studies of isms
teenage revelations
midlife crises

clichés that tire me
and my only desire is
to know
the unknown

But it was not until my seizures peaked in college, when I had the good luck to enroll in a poetry class, that I began actively writing about my experiences. The qualities I saw as a child, I found more words for, and I focused my writing around certain themes: perfection, unity, clarity, reality, harmony, timelessness. If I were to notice a moment, to feel a heartbeat, I would see these qualities infuse the spaces around me. If I dwelled there long enough, I would describe the experience as wanting to be attached, to find a conveyance to manifest it, but the instant you think that, it passes to memory—still beautiful, but now once-removed. Thus, the conundrum of adequately explaining it. Could anyone do justice to a moment passed? I felt very distinctly that something was missing, that there was something I was required to say, but could not. This feeling of entrapment was conveyed in a college poem:

Thorned Doorway

I had not fear
for what I saw, but for
that it was not what I should see
for that side welcomed me
but the doorway was thorned
and so many times
I passed through
and this side
called me
but turned back and shunned me
and so many times
I passed through –
my own glimpse of truth
waged a battle

with whom?
and both sides pulled me
as I bled in the doorway
that so many times
I passed through

Four months after my surgery I was married, and one month later I began graduate school. My seizures had stopped, and although my doctors recommended that I keep on the anti-epileptics, I decided to discontinue them. I was living the “normal” life I had wanted, but my previous experiences lingered around corners and doorways, and I wanted to find their beauty again. Five years post-surgery, I wrote in my journal, “Where are you my little thought?” I remember lying in bed and looking at the corner of the ceiling and trying intently to see my vision.

And there it presented to me, the heartbeat came and went, and I remembered. I went back to journaling and to poetry, to cultivating my experiences, with the feeling I had previously of something missing now evaporated.

Poetry as a Means to Relate Experiences

Poetry has several attributes that make it uniquely well-suited to conveying experiences of transcendence and selflessness. Three such attributes that emerged with special importance to me were: 1) parsimony, 2) shifting perspectives, and 3) playing with the ineffable. The idea of parsimony—that the simplest solution is best, that economy of explanation is required (ie, the rule of Occam’s razor)—is a nearly perfect metaphor for what I felt during my experiences. A desire to convey all things in a simple word was really the vision itself. I sensed this aspect as having qualities of

smoothness and sharpness in a way that could not possibly be improved upon, and wrote of it in the poem “Fuyo,” a Japanese word that means “hibiscus” and sounds identical to a word meaning unnecessary or useless. Fuyo implies that nothing can add to the beauty of an object, because its beauty is already unsurpassable:

Fuyo

A final stroke of masterpiece
 perfection is a clever word
 let loose
 a slippery word let
 slide
 my feet align the edge of a lake,
 water reflects my face
 a portrait framed by melting ice
 I am bit by the cold
 chilled by the silence, but –
 crack! It is broken by
 the word that answers all questions
 all-encompassing
 humble and simple, alone
 the only
 balances
 on the point of a pin

The second attribute that poetry naturally provides is the possibility to write from different perspectives.²⁸ A poet may step into any shoes, seeing the world as easily *from* the self as *toward* it. Poetry is a genuinely accurate portrait of self and ‘non-self’ because both reader and writer attach their own unique sentiments and interpretations to the open phrasings and familiar words. The ‘selflessness’ I practiced prior to my surgery felt much like a conversation between a reader and writer, a mirroring between myself and the world, and I have since written many poems from different perspectives, including:

Self

I see the earth through birds’ eyes
 feel the sea floor’s texture
 I saw rocks as my bones
 and air as my blood
 my veins the limbs of trees
 and flowers unfolding
 I could not tell them from me
 the stars when they shine
 are a tingle in my limbs
 this heart and strong lungs
 I know now their purpose
 to nurture this skin
 that encloses the world
 me and the bare universe

The last attribute to note here addresses mysticism’s common theme of ineffability—the idea there is something important to say, but that the correct words for it cannot be found (eg, Armstrong, Dostoevsky, Whitman quotes; Table). One poem has particular meaning to me for its attempt to capture this fleeting, indescribable thought, or riddle. As described above, my experiences dwelled in the sense of sight, around forms with clean lines, in perfect spaces or things that seem to be equally as much what they are not, just as what they are:

The Little Yellow Chair

I think
 I dreamed
 not an image
 but a thought
 this thought
 this divine thought
 from empty space across the room
 near the corner
 enclosed area of air
 my idea sprung from there

and returns there, remaining
 it isn't the gliding of goodness there, which needs
 surfaces, is surfaces, solid staying
 it isn't evil there, the smoke that clouds, billows,
 subsides, does not cling
 it is the background that lingers there, the rest
 it has not changed since the first I saw it

Like that little yellow chair
 it is not that the wood is warped
 or even the air around it bent
 it is the space there that folded
 or time chose to curve
 and slowed down the truth
 so that it hung there, in the air
 around
 that little yellow chair

As soon as I could write a phrase that I felt captured a moment, all the angst I felt about something “missing” disappeared. The *expression* was the thing I had been missing, the unspoken undertones between different worlds. In my experiences, the seeing of something so perfect but lacking the words to explain was excruciatingly painful. The poet Walt Whitman captured this feeling: “Do you see O my brothers and sisters?” (Table). Then, increasingly over time, simple and common everyday things gave me glimpses of my experiences that I felt expressed them in ways others might understand:

Dresser Drawer

The voice that I hear
 it begins there
 as words adrift on the air
 a feather dropped from a high-up bird
 ideas untold like wings unfold
 like a breath it begins
 but ends like a flurry

that is the way it is with words
 they begin on their own
 to be pasted on the background
 at first disguised
 they seem to be out among the palms
 and layered into the blue sky
 and seem to lie in the night-ness beyond

...words are glimmering, hung about, and my coming upon the thing I want to say—I mean the act of realization—is a perfect metaphor. Like when I opened the drawer of my dresser tonight while I wondered what to write about. I opened the drawer and saw something new and felt something new and knew it had to do with writing. It is a perfect metaphor because it not only represents the thing I'm thinking of, but it is the thing itself. And it is non-fiction. Ideas and words are everywhere, stuffed in the dresser, turning up behind the socks I never wear.

Rehabilitation Implications

This case study demonstrates the importance for rehabilitation professionals, patients, and family members to be made aware of the positive experiences, the *abilities*, that may be associated with disorders, or “disability.” We argue this is especially true in case studies such as ours, in which right-hemisphere neurologic conditions may result in selfless, transcendent, ecstatic, and/or mystical experiences. Such individuals stand to benefit greatly through deeper understanding and relating of these experiences, particularly given their commonly-reported desire to express their thoughts and experiences.

Traditional outlets (eg, recreation therapy, speech pathology, counseling) for such individuals may provide more positive outcomes when they include

options for expressive writing or other modes of art therapy. Poetry has long been recognized as an invitation to listen, a request to take the time to notice subtleties and accept ambiguities.^{27,28} And while generally viewed as a method to heal or cope with illness,^{29,30} poetry—and creativity in general—has been suggested to be a welcome attribute of some illnesses.³¹ Such recognition of a potential link between psychopathology and creativity has received considerable attention in the literature, and its discussion is beyond the scope of this paper. Nonetheless, we emphasize that recognition of positive aspects to “disability” need not come at the expense of accepting traditional scientific diagnoses or discussion of impairment. As our case study demonstrates, the two perspectives are not at odds; the understanding of the neurologic condition and medical basis of selfless experience provided this author with additional validation to pursue creative outlets.

Seeing sciences and humanities as a continuum rather than dichotomy provides just the type of reconciliation that a patient compelled to find unity in their world requires.

In summary, we hope this case study will serve as one model through which clinicians may work with patients to discover often hidden positive aspects of their condition. We offer these insights especially for those facing “disorders” of the self and/or mystical experience, but also to the broad community of rehabilitation professionals, patients, and philosophers alike, seeking to reconcile physical and spiritual experience by bringing sciences and humanities together

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Table. Quotes on Transcendence, Self, and Expressive Writing.

Author	Quote
Karen Armstrong	<p>“I am trying to describe an experience that has nothing whatever to do with words or ideas and is not amenable to the logic of grammar and neat sentences that put things into an order that makes sense. Maybe I could explain it better if I were a poet... Suddenly – at last – all the conflicting pieces of the pattern seemed to fuse into a meaningful whole. I had entered a new dimension of pure joy, fulfillment, and peace: the world seemed transfigured, and its ultimate significance – so obvious and yet quite inexpressible – was revealed.” – <i>The Spiral Staircase</i>²⁰</p>
Fyodor Dostoevsky	<p>“There are seconds, they come only five or six at a time, and you suddenly feel the presence of eternal harmony, fully achieved. It is nothing earthly; not that it's heavenly, but man cannot endure it in his earthly state. One must change physically or die. The feeling is clear and indisputable. As if you suddenly sense the whole of nature and suddenly say: yes, this is true.... What's most frightening is that it's so terribly clear, and there's such joy. If it were longer than five seconds – the soul couldn't endure it and would vanish. In those five seconds I live my life through, and for them I would give my whole life, because it's worth it.” – <i>Demons</i>²¹</p> <p>“There is something at the bottom of every new human thought, every thought of genius, or even every earnest thought that springs up in any brain, which can never be communicated to others, even if one were to write volumes about it and were explaining one's idea for thirty-five years; there's something left which cannot be induced to emerge from your brain, and remains with you forever; and with it you will die, without communicating to anyone perhaps the most important of your ideas.” – <i>The Idiot</i>²²</p>
Walt Whitman	<p>“There is that in me—I do not know what it is—but I know it is in me... I do not know it—it is without name—it is a word unsaid, It is not in any dictionary, utterance, symbol. Something it swings on more than the earth I swing on, To it the creation is the friend whose embracing awakes me. Perhaps I might tell more. Outlines! I plead for my brothers and sisters. Do you see O my brothers and sisters? It is not chaos or death—it is form, union, plan—it is eternal life—it is Happiness” – “<i>Song of Myself</i>” Part 50 in <i>Leaves of Grass</i>²³</p>

St. Teresa

“...The soul understands he is there, though not so clearly. She does not know herself how she understands; she sees only that she is in the Kingdom.... It is like the suspension of all internal and external powers. The understanding desires to know but one thing, and memory to remember only one. They both see that only one thing is necessary, and everything else disturbs it...I think therefore that since the soul is so completely happy in this prayer of quiet, the will must be united during most of the time, with Him who alone can satisfy it.” – *The Way of Perfection*²⁴

About the Authors



Michèle R. Slaton, PhD is a vegetation ecologist living in Bishop, California. She received a Bachelor of Arts degree in Biology from Reed College and a Doctorate in Botany from the University of Wyoming. She is passionate about the study of philosophy and finds hope and solace in the commonalities of science and poetry.



Brick Johnstone, PhD, ABPP is Director of Acquired Brain Injury Research at Shepherd Center in Atlanta, Georgia. He is a neuropsychologist who has practiced in rehabilitation for 30 years with his research focusing on employment following brain injury, as well as the neuroscience of transcendence and character traits. He earned his undergraduate degree in art history and psychology and has presented on the representation of disability in the visual arts for nearly two decades, promoting the humanities in educating rehabilitation professionals and students.