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Identity, Hospital, and Cancer: The Story of Lucy Grealy

By Florina Catalina Florescu¹

Dedicated to parents who helplessly witness their children dying, and especially to my grandmother.

“Who are *you*?” said the Caterpillar. This was not an encouraging opening for a conversation. Alice replied, rather shyly, “I—I hardly know, Sir, just at present—at least I know who I *was* when I got up this morning, but I think I must have changed several times since then.” “What do you mean by that?” said the Caterpillar, sternly. “Explain yourself!” “I can’t explain *myself*, I’m afraid, Sir,” said Alice, “because I’m not myself, you see.” “I don’t see,” said the Caterpillar. “I’m afraid I can’t put it more clearly,” Alice replied, very politely, “for I can’t understand it myself, to begin with; and being so many different sizes in a day is very confusing.”

Lewis Carroll, *Alice in Wonderland*

Keywords: Literary criticism; Self-image; Cancer; Hospitalization; Suicide

Lucy Grealy was diagnosed with cancer when she was very young. Her childhood was seen, felt, transcribed into feelings from a traumatic point of view. Because of the visibility of her cancer, she suffered additional cruel remarks, all an immature cliché (i.e., “monster” or “Frankenstein”). Grealy discovered and revered her invisibility either in hospital, among other patients, or during the night of Halloween, where, under a mask, she had a few hours of freedom of looking at the world without being stared in awe and poorly judged.

After invasive treatments, Grealy managed to be cancer-free. But her face was still not symmetric; she underwent about 30 plastic and/or corrective surgeries to complete an image, and, an identity, that stubbornly refused to be fulfilled. In other words, no matter how many risky surgeries she had (to a certain extent, as self-punishment and/or self-mutilation), regardless of how many tissues were taken off from various parts of her body and grafted onto her face, the result was only temporary, eventually succumbing Grealy into spiraling disaster.

We hope words such as “cancer,” “chemotherapy,” and “suicide” will be avoided from our dialogue. In fact, we hope to never have to confront them. Some are, indeed, lucky. Others, like Grealy, are positioned by fate at the gate of hell, uncertainty, and misfortune. For this reason, some taste daily drops of death through an invisible to others

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IV pole. In order to keep her pain at a somewhat tolerable level, ever since the diagnosis of cancer, Grealy depended on drugs, some of which were very potent. One unfortunate day, she could not take it any longer. Although cancer-free, after another failed reconstructive facial surgery, pain moved into unstoppable agony and despair. She committed suicide by an overdose of drugs.

Her cultural legacy is a memoir of invaluable literary power, in which she speaks about her struggle with cancer, and, more importantly, about her confrontation with pain, suffering, depression, and fluctuating identity. Grealy's *Autobiography of a Face* (2003) initiates a quest for the contemporary invention of the self that is disjoined from the humiliation of tormenting physical suffering, even if that implies suicide. As argued, for people like her, who cannot overcome their status as patients, suicide is a justified step to complete and validate their journey into life interrupted by constant pain. Finally, for Grealy, suicide means finding dignity as a genuine response for a life performed on a restrictive stage of bodily incarcerating deformity.

[II]

"Once upon a time" is the formulaic, initial sentence of most fairytales. It entails the premise of a fictional universe saturated with dragons, charming princes, white-as-milk castles, magic wands, ballrooms, and wicked characters eventually caught and taught a lesson. If there is something that is excluded from this promising narrative that is the lack of pain, or, at least, its eventual defeat. Furthermore, childhood implies transacting life at the level of a series of novel sensations and experiences: first friendship, first kindergarten teacher, first diary, first membership in a club, and first time reading by oneself. There is a steep separation between playing with dolls and cars, hide-and-seek, singing funny songs, and reciting silly rhymes versus preparing for one's first surgery, first chemotherapy session, and first prolonged hospitalization. This is the story of a brave young girl, who had her first dental cyst surgery at nine years old.

While her body pursues its anatomical development (from infancy, childhood, adolescence to maturity)--although considerably impaired by the various very strong medicines--her mind retains a magnetic quality of recording raw, cruel discoveries: first incision on the skin, first unexplained bleeding, first acute pain, and first trick to somehow put to rest the body that keeps raging with frustrating ache.

This essay approaches agony from the interception of "to be" with "to perceive." According to the French phenomenologist philosopher, Maurice Merleau-Ponty, "To be a consciousness or rather *to be an experience* is to hold inner communication with the world, the body and people, to be with them instead of being beside them" (111). Incarcerated in a sick body, and in a hospital and at home, Grealy holds a distinct connection with the outside world.

From infancy onward, we engage in many activities. There is a (scheduled) time to eat, a time to play, and a time to sleep. In his book, *Space, Time, and Medicine* (1982), Larry Dossey argues that "Without a clear idea of the concept of time, we cannot understand its impact on our health, nor can we appreciate how the sense of time can be manipulated in ways to make us healthier" (21). Grealy detects too soon the cruel, non-fictional dimension of existence. Post surgery, she endures the alienation effects of hospitalization, a neutral institutional environment that, ironically, is about to reform itself into her shelter for identity.

Along with other young patients, they create their ad-hoc, unofficial “secret league” of different kids, a sort of cheerful organization and an organic reaction to acting their age. As she recollects, “Getting there [to a room where they showed kids cartoons] was half the fun, passing through the main halls in our slippers and bathrobes, passing people in their street clothes. It was as if clothes spoke to each other, our childish pajamas murmuring something special about us as we brushed past the suits and white coats and work clothes” (41). These sick kids are in a special place, where they may still take part in the joys of childhood (eating rice or vanilla pudding, watching cartoons, and playing games); at the opposite end of the spectrum, they have already started to detach themselves from normality as endorsed by the repetitive cycles of social activities.

Within this secluded habitat, Grealy tiptoes on the fragile “stage” of the impotent body, namely an embodiment that is more an object (meaning acted upon) than a subject (acting out). According to Elizabeth Grosz, “For a subject to take up a position as a subject, he must be able to situate himself as a being located in the space of his body. This anchoring of subjectivity in *its* body is the condition of coherent identity” (89). A hospitalized identity is always disjointed and cracked, depending on numerous clinical tests and uncertain results of prescribed treatments. Such a selfhood crawls on slippery memory, more specifically on those secure moments of the past when the person was intact and s/he did not have a diagnosis.

Furthermore, Renaud Barbaras claims that “[b]odies that perceive are *living* bodies and [...] are distinguished from other corporeal beings [...] by their capacity for *movement*. [...] To determine the true being of the subject, it does not suffice to grasp it as incarnated, [but instead on] a constitutive characteristic of *its* incarnation” (86). Grealy’s confinement in the hospital situates her on the rim of language. The “Who am I?” question transforms into “Why can’t I make this body function properly?” In the beginning, the idea of being other thrills Grealy immensely: “I wanted nothing more than to be special, and so far the role of patient had delivered” (25). As patient, she can easily stand out in her group of friends at school or at home. This newly added feature to her personality is undoubtedly more appealing than projecting herself a princess, an obsolete platitude.

At this point, being patient is still tolerable and, even though she deals with physical discomfort on a daily basis, at least there is the promise of its cessation. As soon as she starts her chemotherapy sessions, her outlook on reality changes drastically:

I began to grow warm, a caustic ache began setting into my elbow. For a spilt second, [...] the sensation was almost pleasurable, a glowing, fleshy sense of my body recognizing itself as a body. But immediately it was too much: I felt the lining of my stomach arc out and pull spastically back into itself like some colorful disturbed sea anemone. It was an anatomy lesson. I had never known it was possible to *feel* your organs, feel them the way you feel your tongue in your mouth, or your teeth. (75)

The next step in this unscripted, hellish scenario is to obsessively absorb what others think, to occupy their healthy space and, thus, feel what they feel. In a manner of speaking, to let herself partake in the events of normal life, since, by ill chance, her cancer has irrefutably stolen her social identity. While at home, she thinks of herself a

visitor--an estranging self-generated reflex despite that "The house itself mothered me" (81). However, a house is animated when there are other people, too. Otherwise, it resonates its emptiness. Such an intimate establishment becomes her second hospital. Despaired, "I became a snoop, going through everyone's drawers, looking for clues to how other people lived their lives" (81). This is the confession of a child, who, after has suffered a great deal of pain, encounters the obstacle of sensing herself unless she dresses up in many familiar "costumes" from an improvised, impromptu theater closet.

Reasonably enough, she develops nostalgia for hospitals because they elicit "[t]he vague longing that attaches itself to almost any version of the past" (93). To a certain degree, she had some sort of uninterrupted companionship there: a nurse, a doctor, a fellow patient, his/her visitors, Grealy's family members, and her fluctuating bodily fragility. Robbed by a standard childhood, she faces the adversities of being (equated with) an outcast. She is not yet allowed to go to school because she is not fully recovered. She cannot return to the hospital either because her pain has reached safe levels to be monitored at home, without the supervision of any medical staff. She experiences destitute loneliness in a habitual place that is supposed to be a shield for her fears and a comfort to her problems. Or, as Julia Lawton explains, "Patients' experience of 'isolation with their disease' [changes] their sense and perception of time [so that] time [becomes] radically different from that of their family and friends" (46-47). Whenever there is a constant nightmare, time outside of its volatile borders becomes more precious and intense, yet infinitely scarier. Grealy does not know when her body will feel *again* too weak to stand on its own, without the ingestion of tranquilizers: "We kept the refillable prescription bottle in a kitchen cabinet, and within a short while I was taking pills almost constantly, even when I wasn't in pain" (142).

It is a truism to admit that pain is an inevitable coordinate on our reality's axis. But what is its meaning? Grealy has often attempted to dig out pain's linguistic justification/definition: "I can reconstruct now that its [malignancy's] important syllables probably charmed me, its promise of rare and dangerous implications made me feel important, but its lack of meaning provided me with just enough echo to act as background to my shock at hearing the word *cancer*" (44). She goes further advocating that "Language supplies us with ways to express ever subtler levels of meaning but does that imply language *gives* meaning, or robs us of it when we are at loss to name things?" (44) She faces her pain and cognitive fears simultaneously. Interestingly, the etiology of this illness is uncertain, and people with apparently the same type of cancer (i.e., colon or breast) may react antagonistically to identical prescribed treatments. Therefore, it is not language that is investigated or questioned; it is also each individual's body's constitution.

All of a sudden, there is a new décor. There are screams of joys and excitement. There are carousel and rollercoaster rides. Some enjoy them, while others feel dizzy and nauseated. At a smaller scale, we may repeat this experiment with cancer, which is a random mutation at the level of cells. Its cure is also a matter of luck, and not exclusively of advanced medical equipment and techniques, early detection, behavioral management (repeated exercises of relaxation and self-control, but never self-pity!) and other genetic and social factors. Grealy does not know how to name her experience because she has been facing cancer since she was a child, an otherwise moment of ingenuity, abounding with games and inquiries, and not with inconclusive, teasing clinical tests (that may only

magnify her isolation). This finding ends abruptly a chapter in her development: “Once upon a remote, foggy time, there was life outside the jurisdiction of cancer. That life is forever gone.” She suspects that language mocks her pain, and it is not able to faithfully transmit her anger and disgust at an unjust fate.

[III]

To increase the degrading embarrassment of such a disappointing life, Grealy points out that “Later, as I underwent more and more operations, even when I was at home in my own bed, upset about how much I hated my face, I could put myself to sleep by imagining myself lying on a stretcher” (145). The image of a stretcher as a soporific agent is amazing. In a blink of an eye, her body is miraculously enchanted by a force attracted only by her mind. While kids find comfort holding closely a teddy bear or listening to softly sung lullabies, Grealy believes these methods to be false or inaccurate to soothe her wounded personal history. In the midst of her teen years, she recognizes that there is a phase of silliness to which she had limited access and exposure, but there is the adult world, too. In the latter, lies may harm people more than facing cruel and disappointing truths.

As in a previous quote, when she admitted frankly that she took pills before she even felt pain (to prevent it taking control over her body), she brings into view another disturbing image, that of a stretcher, which, paradoxically in her case, acquires a positive message. Kids travel on magic carpets and have imaginary, translucent wings that take them away from boredom and trouble, but Grealy has a palpable or a projected aide in the form of a medical stretcher. The assumption is that, maybe, she will outsmart pain by vicariously offering her body. Over the years, she has become an expert at flexing her physical territory. When she was left alone for hours, while others were in school or at work, she perfected this ability to stretch her body and mind. She could lie indefinitely on her twin sister’s bed noticing what she saw daily through her room’s window, playing with her sibling’s reality like in a jigsaw puzzle. Later, she would recline on a stretcher pretending to be an extension of a magic wand invested with the miracle to end her agony.

In his book, *The Consuming Body* (1994), Pasi Falk argues that “The human body occupies an ambiguous, even paradoxical role in cultural categorizations. It is the most obvious and familiar visible ‘thing’ perceived and yet a blind-spot which tends to disappear in the very act of perception” (1). Even if Grealy has not ever found an acceptable explanation for her cancer, she nonetheless imposes language to play her a version of suspension of disbelief. Oftentimes, she imagines herself dis-embodied and, thus, floating away from pain. She locates herself within the darkest spaces of her intimate discourse by masterfully switching from one epicenter of pain to its valve release via imagination. She moves from “This body hurts terribly” to “This is how my body should have acted if it was pain-free.” Grealy is on the verge of a wonderful discovery. She implies that even though pain is tragic, it is not our supreme force. Human beings have the infinite at their feet provided they borrow their mind to visions. In other words, her hurt identity allows Grealy to be a rebel, an unconventional author, and to intervene in her narrative whenever reality is insufficient and gloomy to satisfy her needs.

Moreover, to be patient means to perceive oneself as subject and object without no or minimal chiasm, to experience a more elevated reaction to the classical divide. Sue

E. Cataldi emphasizes that “Phenomenologically, our sense of ‘self’ is that we are simultaneously open to and closed off from others. [...] Similarly, our ‘lived’ experience of the world is that we belong to it or are of it, but are not it” (28). Because perception needs an “interlocutor” to validate itself, as subject and object, a patient relies on his/her reciprocity to initiate a dialogue. Grealy has been at “war” with her body ever since she was nine. In return, this selfish, violent confrontation made her body a “casualty” than a possession. After three gruesome years of chemotherapy, Grealy’s teeth and lower part of her face were strongly mutilated. To correct this severe physical deficiency, she would undergo several surgeries. This would determine her to revise the insecurities of language as well as of medical practice. Put differently, in the beginning, doctors could not find her a precise diagnosis. She had a broken jaw, a dental cyst, and, finally, Ewing’s sarcoma (i.e., a rare form of cancer, located in the bone and soft tissues). With this dental work to be done, doctors would attempt many surgical maneuvers--both old and new--so that she would be completely exhausted. Moreover, she would be deprived of time to stick with an image and accept it as her own.

[IV]

We notice the mirror and its elusive reflections from childhood. At first, infants think they encounter a stranger when they see themselves visually repeated. Later, they realize their unique embodiment. The invention of the intimate, reflected identity is tantamount to the construction of the social self, and it probably lasts for the rest of one’s life. We look in a mirror constantly in search for an answer that is never conclusive because it has many variables: our moods, interests, and external stimuli. Because we are used with accepting our echoed image as our disposable, instant visual twin/alter ego, we rarely have a shock when we meet its photographed representation. We recognize ourselves effortlessly in thousands of photos, and we appraise our evolution smoothly, since it is part of a process which we have witnessed consciously over the years.

Sick persons become aware of yet another type of visual double. As Grealy recollects, “I stood there perfectly still, just as I had sat for countless medical photographs: full face, turn to the left, the right, now a three-quarter shot to the left” (11). This kind of photo has little to nothing in common with the delights associated with a family photo portrait, a snapshot, or a photo taken in the company of a friend. Medical photographs fulfill solely their assigned rigid purpose, and request of the sitter to maintain an eerie stillness, so that s/he may not tamper with the scientific evidence. Medical camera does not capture a smile, a frown, or an anxiety because it is emotionless. Neither does it sense one’s body’s rhythm. Medical camera is an apparatus and, consequently, it admits nothing but one’s motionless.

In his essay, “Understanding a Photograph,” John Berger contends that “A photograph, whilst recording what has been seen, always by its nature refers to what is not seen. It isolates, preserves, and presents a moment taken from a continuum. [...] The language in which photography deals is the language of events. All its references are external to itself” (293). By contrast, medical photography intends to reveal what is beneath the opaque meat by opening up its darkness. The language of events that medical photography refers to translates a body’s internal communication, later to be mediated by a physician.

For Paul C. Sorum, “As ‘reader-response’ theorists point out, each reading is necessarily a reconstruction of a text. By rewriting in medical terminology, physicians [...] put patients’ texts into more abstract terms, transforming patients into cases” (549). He also notes that “[t]he patient is a historian. Her form of history is narrative, not only analytic. [...] Her repeated versions of the story are anchored by certain common events and formulaic expressions” (550). We need to interpret these quotes from the point of view of a child, who is not yet fully equipped emotionally to grasp this frozen version of reality, because his/her mind is plastic and capable of changing roles. One minute, a child flies on an imaginary plane, then s/he embarks on a Vikings’ boat; one instant, a child sits on a cotton candy cloud, after that s/he swings back and forth on a rainbow on a sunny summer day. These are typical children’s images. To this precious, infantile childhood repertoire, Grealy adds the dryness presented by medical photos developing into (sometimes life-threatening) medical cases.

Grealy does not have an alternative but to combine these two opposed realities. While sitting still for a medical shot, she may hear in the back of her head silly verses: “Humpty Dumpty sat on a wall./Humpty Dumpty had a great fall;/All the King’s horses, and all the King’s men/Cannot put Humpty Dumpty together again.” By ill fortune, she may even feel an actualized, incarnated Humpty Dumpty. As sad irony, no doctor will ever be able to put Grealy up again because there is an unfortunate, tricky intruder in her embodiment stubbornly rejecting all fixings. As a consequence, she does not have time to accommodate herself with any of her successive asymmetrical facial versions. She may even be under a protean spell: she may change as many times as she pleases, but she will never know why this happens. In this context, a pertinent moment is when she asks permission to dress up for Halloween:

I begged my mother to let me go out. I put on a plastic witch mask. [...] At home, when I took the mask off, I felt both sad and relieved. Sad because I had felt like a pauper walking for a few brief hours in the clothes of a prince and because I had liked it so much. Relieved because I felt no connection with that kind of happiness: I didn’t deserve it and thus I shouldn’t want it. It was easier to slip back into my depression and blame my face for everything. (127)

These feelings of self-imposed punishment are a result of years of intense medications and invasive treatments that will continue to harm Grealy for the rest of her life. She cannot be a care-free child and adult because she is scarred by recurrent, unstoppable pain.

[V]

Adjusting to an external identity that is literally under knife--in surgery--requires a great deal of courage, because it implies a permanent state of deferral. No one could predict any clear-cut result or promise to be satisfied with the outcome. Grealy underwent three years of chemotherapy and about 30 surgeries to correct the damage made by cancer. Of all these risky interventions, what is about to be quoted pertains more to a surreal movie script than a real-life situation. When I read it, I was breathless. When I

transcribed it in my notes, I recoiled under my skin, ashamed to acknowledge sensations of tremor, disgust, and pity:

In the first operation, two parallel incisions would be made in my stomach. The strip of my skin between these incisions would be lifted up and rolled into a sort of tube with both ends still attached to my stomach, resembling a kind of handle: this was the pedestal. The two incisions would be sewn together down its side, like a seam. Six weeks later, one end of the handle would be cut from my stomach and attached to my wrist, so that my hand would be sewn to my stomach for six weeks. Then the end of the tube that was still attached to my stomach would be severed and sewn to my face, so that now my hand would be attached to my face. Six weeks after that, my hand would be cut loose and the pedestal, or flap, would be nestled completely into the gap created by my missing jaw. This would be only the first pedestal: the whole process would take several, plus additional operations to carve everything into a recognizable shape, over a period of about ten years altogether. Ten years! I was horrified. (154)

This *abbreviated* passage demonstrates that Grealy had an almost invincible will to correct her face, and put an end to her ordeal of attaining *one* stable facial identity. This fragment also speaks about medicine's capacity to design the impossible, and to fight against the forces of anatomy. But that is never enough. Grealy lacks fortune or the most fundamental element to any recovery. All these surgeries prove effective for a short period of time, teasing her. Once the tease subsides, the tissues reabsorb themselves as a side-effect of numerous years of irradiation. She craves to find her final external representation, but that is impossible to reach. Her face is her own Sisyphus' rock, and, no matter how hard she pushes it to reach the hill's top, the rock returns to its initial starting point.

When she realizes that this effort is futile, she is determined to have an opposite approach to life, by eliminating the mirror. To her amazement, she realizes that there are multiple reflective materials that surround us, as if we were in a mirrored theme amusement park: "I never suspected just how omnipresent our own images are. I became an expert on the reflected image, its numerous tricks and wiles, how it can spring up at you at any moment from a glass tabletop, a well-polished door handle, a darkened window, a pair of sunglasses, a restaurant's otherwise magnificent brass-plated coffee machine" (220). These various reflected images, lurking in a dangerous, unknown place, must have overwhelmed her. They may imply a return to Argus, the mythical giant with one hundred eyes sewn on this body to monitor everything and stare back in awe. Even more poignantly, while Grealy searches for her "I," she finds the omnipresent "eye," always prepared to (mis)judge based on appearances. All these duplicates of her face deteriorate themselves into a chorus of mean voices that emit the same message about her ugliness.

She hates her face and wants to mask it, but *where* does one hide one's face?! Unlike other marked sites of our bodies, where scars are signs of past trauma, our face is the most exposed part. It speaks about who we are from a collection of inborn physiognomic features to wrinkles, holes, scars, etc. It is the locus of the mouth that

verbalizes our thoughts, of the ears that listen to what others have to say, of the nostrils through which olfactory sensations infuse our bodies, and of the eyes with which we marvel at the manifestations of the world.

During her few years of maturity, she starts to slowly give up on acquiring an image. She considers her face to be of on “an ugly intruder” (157), someone who reluctantly refuses to go away. Having learned to master the vertigo effect of the reflected images, she is an expert in what society labels “standard beauty,” describing it as shallow, vain, and personally inconclusive. As she remarks, “Unlike some stroke victims, who are physically unable to name the person in the mirror as themselves, my trick of the eye was the result of my lifelong refusal to learn *how* to name the person in the mirror” (221). It seems that she had to live with a constantly manipulated and medically operated upon person(a), that, in the end, her life outside pain was vague, *one* distant dream. Perhaps she did not even exit childhood, since she never had the chance to exhaust all its treasures.

She pens a memoir about her face and its unjust episodes of ordeals only to remind us that we should *not* take anything for granted, including our possessions, awards, manners, strong points, and weaknesses as long as everything is mutable, ever changing. She admits that “[m]ost truths are inherently unretainable, that we have to work hard all our lives to remember the most basic things. Society is no help. It tells us again and again that we can be ourselves by acting and looking like someone else, only to leave our original faces behind to turn into ghosts that will resent us” (222).

Her epiphany speaks about a childhood luxury, when we tend to project ourselves as invincible and eager to impress characters. Typically, adulthood crushes these fantasies as we enter the narrow, factual cubicles of our social, estranged lives. Pain, even more than anything else, makes us bold and resuscitates our passion for living. However, prolonged physical suffering, hospitalization, surgeries, and pills cripple one person’s identity and self-confidence. It was in the hospital where Lucy Grealy felt socially fully developed, surrounded by a cohort of patients. In was in suicide that she finally finished off a face. Abandoning agony, she finally steps on her own version of “forever after,” where she meets her blessed, too long awaited, *seamless* external self, and, therefore, puts her obsessive search at ease.

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