Face off: searching for truth and beauty in the clinical encounter

Based on the memoir, autobiography of a face by Lucy Grealy

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Abstract Based on Lucy Grealy's memoir, *Autobiography of a Face*, this article explores the relationship between gender and illness in our culture, as well as the paradox of "intimacy without intimacy" in the clinical encounter. Included is a brief review of how authenticity, vulnerability, and mutual recognition of suffering can foster the kind of empathic doctor-patient relationship that Lucy Grealy sorely needed, but never received. As she says at the end of her memoir, "All those years I'd handed my ugliness over to people, and seen only the different ways it was reflected back to me."

Keywords Philosophy · Narrative medicine · Doctor-patient relationship · Gender and illness · Health care

Not every patient can be saved, but his illness may be eased by the way the doctor responds to him.
Anatolle Broyard.

Introduction

Near the end of Anne Fadiman's book, *The Spirit Catches You and You Fall Down*, a tragic account of two cultures at odds with each other, she tells the story of a Hmong patient who was being referred to a specialist for further treatment, and instead of inquiring about the physician's skill or credentials, he asked, "Do you know someone who would care for me and love me"? (Fadiman 1997) It is an honest

question that bears asking, and yet in all its naked simplicity lays the deepest complexity. It is not the kind of question one answers quickly or without reservation, but it is a question that deserves a thoughtful answer.

We see this same question come up again in Lucy Grealy's memoir, *Autobiography of a Face*, where she details her own search for someone to care for her and love her, but after almost thirty surgeries to repair her deformed, cancer ridden jaw, she still can't find anyone to look past the edge of her wound, to listen past the edge of her silence. Sitting under the glare of fluorescent ceiling lights in exam room after exam room, Grealy is too young and too proud to ask the question out loud, and yet if one listened closely, it could easily be heard just under the hum of silence, seen just under the veil of downcast eyes. It would not be incorrect to assume that beneath our own culture's ideal of independent selfhood lies the very same question, for when all is said and done, isn't this what every person desires? Unfortunately for Grealy, beauty equaled love. It was the condition upon which all else hinged: her perception of self and other, her struggle for recognition, her quest for identity and ultimate search for truth. "I was my face, I was ugliness," says Grealy (1994). Living in a culture where beauty is an encouraged and sought after ideal, she could not escape the reflection from our own unforgiving mirror.

Drawing upon the philosophical tenets of Hegel, Butler and Levinas, this paper will explore the relationship between gender and illness in our culture, as well as the paradox of "intimacy without intimacy" in the clinical encounter. Included will be a brief review of how authenticity, vulnerability, and mutual recognition of suffering can foster the kind of empathic doctor-patient relationship that Lucy Grealy sorely needed, but never received. As she says at the end of her memoir, "All those

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years I'd handed my ugliness over to people, and seen only the different ways it was reflected back to me" (222).

Intimacy without intimacy in the clinical encounter

Most coming of age stories revolve around family, friends and school experiences, but Grealy's story, and consequent primary frame of reference was the hospital setting, where she spent most of her formative years recovering from multiple surgeries. She began her journey into the medical world at age nine, that precarious age that straddles childhood and pre-pubescence, and continued living in that world, on and off, throughout her college years and into young adulthood. The impact of this contextual frame of reference was paramount in shaping not only her sense of self and other, but her perception of her place in the world.

The chronicity of illness places special demands on the doctor-patient relationship, and in Grealy's case these demands were compounded by her own psychosexual development, where an unconscious regard for the doctor was not only one of healer, but also one of mother, father, friend, and confidante—all relationships of caring and intimacy that form the intersubjective dimensions of our lives. Across history we see the powerful and significant roles which physicians play in any given culture, consistently demonstrating their elevated social standing. Writer and author, John Berger, speaks to this when he writes about the primitive medicine man as "priest, sorcerer and judge, who was the first specialist to be released from the obligation of procuring food for the tribe. The magnitude of this privilege and the power it gave him is a direct reflection of the importance of the needs he served. An awareness of illness is part of the price that man first paid and still pays for his self-consciousness. This awareness increases the pain or disability. But the self-consciousness of which it is the result is a social phenomenon and so with this self-consciousness arises the possibility of treatment, of medicine" (Berger 1997).

It is within this realm of self-consciousness where recognition of the Other is necessitated, for as the philosopher Georg Hegel states, "Self-consciousness achieves its satisfaction only in another self-consciousness ... it exists in and for itself when, and by the fact that, it so exists for another; that is, it exists only in being acknowledged" (Hegel 1977). This process of recognition represents a coming out of oneself, as it were, a movement between two self-consciousnesses where "each is for itself, and for the other, an immediate being on its own account, which at the same time is such only through this mediation. They *recognize* themselves as *mutually recognizing* one another" (112). This movement is ultimately reflective in nature, and involves a dialectical process of negation whereby two

apparently opposed ideas, the thesis and antithesis, become combined in a unified whole to create a synthesis. In Hegelian thinking this is an unfolding of truth, an unfolding of Self in one's ever evolving identity formation.

Grealy's own search for truth unfortunately resulted in repeated negative reflections from the other. As stated in her early experiences with peers: "I learned the language of paranoia; every whisper I heard was a comment about the way I looked, every laugh a joke at my expense ... I was honing my self-consciousness into a torture device, sharp and efficient enough to last me the rest of my life ... there was only the fact of me, my face, my ugliness" (6–7). Due to her disfiguring illness, Grealy was forced to live apart from her peers. Relegated to a separate, parallel world of doctors and hospitals, the mutual recognition Hegel speaks of could only be found in the doctors Grealy relied upon for her care, and yet her search for such recognition was most often stunted, or entirely thwarted by the time honored, protective shield of "professional distance," the precursor of which can be found in the more traditional dialectics of medical discourse.

As English Professor Thomas Couser points out, such discourse ultimately favors the professional: "doctors exercise their medical authority through their privileged place in a specialized discourse ... Indeed, the crux of the problem of medical discourse may lie in the nature of its relation to the discourse of science: the claim to expertise rests on the prestige of science, but the scientific tendency to objectify and quantify human experience may obstruct the profession's humanitarian intent" (Couser 1997). Grealy attests to what often results from this type of discourse by her comment on a doctor's visit with her mother when she was only nine: "Nothing infuriated my mother more than this condescension, which even I recognized as endemic in the medical profession" (25).

With medical technology's advent and proliferation of increasingly sophisticated diagnostic tools, doctors have become even more distanced from their patients, resulting in feelings of decreased trust and confidence in a relationship that needs and depends on it the most. As physician and author Rita Charon states, "The price for a technologically sophisticated medicine seems to be impersonal, calculating treatment from revolving sets of specialists who, because they are consumed with the scientific elements in health care, seem divided from the ordinary human experiences that surround pain, suffering, and dying ... Patients long for doctors who comprehend what they go through and who, as a result, stay the course with them through their illnesses. A medicine practiced without a genuine and obligating awareness of what patients go through may fulfill its technical goals, but it is an empty medicine, or, at best, half a medicine ..." (Charon 2006). It is not surprising that "this post-modern

experience of illness is distinguished by the impulse of patients to reclaim their bodies and their stories from medical discourse” (5: 11).

Given these upsetting developments in the practice of medicine, the doctor still remains a symbol of hope in a patient’s search for relief from pain and suffering. It is indeed a unique relationship, characterized by a level of physical and emotional intimacy not found outside of the romantic relationship. The vulnerability of a patient who sits nearly naked on a hard exam room table waiting to reveal details of a highly personal nature is often not taken into account by physicians; however it is here where the paradox of intimacy without intimacy lies. When exposure of one’s underbelly for the sake of a cure, of redemption, an ease of suffering, or simply a listening ear is met with the cold gaze of professional distance, the relationship becomes one of compromise where trust is breached and suffering is heightened. And yet it is in this exposure, in this very vulnerability where an accurate diagnosis and healing lie. Vulnerability is transparency in its purest form, and it is only here, within this vulnerability where the physician “can hear the fragmentary language of pain, coax it into clarity, and interpret it” (Scarry 1985).

In a recent interview with physician Pamela Wible, who has devised her own brand of medical practice far a field from traditional practice standards, she states that, “The most important therapy I deliver is a human relationship ... I want to open your medical record and read one or two snappy sentences about who you are. I want my patients’ passions listed on their charts. Because if that’s not there, then the only thing I read is ‘endometrial cancer, carpal-tunnel syndrome, fibromyalgia, chronic fatigue, and mother died when she was forty of breast cancer. I don’t want to look at this person and simply think, *she’s doomed*. I want to know what her passion is in life. Who is this person sitting in front of me? ... People come to the doctor for care and end up with a prescription. We need to get rid of this idea of professional distance and let physicians be vulnerable” (Passaro 2009).

But how can a physician shift from the traditional stance of professional distance to one of relationship? How can he/she relinquish that which has served to protect him from the daily horrors of overwhelming pain and suffering in his patients? How can he forego the biomedical model for a patient centered, relationship-based one? Berger, in his observations while accompanying an English country doctor on his daily rounds says, “He never separates an illness from the total personality of the patient ... He does not believe in maintaining his imaginative distance: he must come close enough to recognize the patient fully ... This individual and closely intimate recognition is required on both a physical and psychological level ... The whole process, as it includes doctor and patient, is a dialectical

one. The doctor ... must first recognize the patient as a person: but for the patient—provided that he trusts the doctor and that trust finally depends upon the efficacy of his treatment—the doctor’s recognition of his illness is a help because it separates and depersonalizes that illness” (73–4).

Physician and author Sayantani DasGupta breaks down the wall of professional distance even further with what she terms “narrative humility,” which she says “acknowledges that our patients’ stories are not objects that we can comprehend or master, but rather dynamic entities that we can approach and engage with, while simultaneously remaining open to their ambiguity and contradiction, and engaging in constant self-evaluation and self-critique about issues such as our own role in the story, our expectations of the story, our responsibilities to the story, and our identifications with the story—how the story attracts or repels us because it reminds us of any number of personal stories. Like diversity training, narrative humility also addresses the hierarchical imbalance of the clinical relationship. It acknowledges that the socially more powerful player—the clinician—must willingly place herself in a position of some transparency. The clinician must not only see, but be seen, and by doing so, enable herself to see ever more clearly” (DasGupta 2008).

By utilizing this process of reflexivity, the physician can develop a more empathic stance with the patient, thereby fostering the type of therapeutic alliance upon which authentic doctor-patient relationships are based. And though the philosopher Emmanuel Levinas reminds us in his essay on exteriority that we can never truly know the other, we can still enact our sense of humility and in so doing, our ability to bear witness to the pain and strife of the other.

While many physicians do indeed provide the kind of deeply compassionate care which Grealy sought, unfortunately she recounts only a single experience where a physician attempted such empathy, which occurred during a meeting to discuss reconstruction of her jaw that he’d removed. She was fifteen, and devastated to hear the whole process would take about 10 years: “I was crushed. It must have shown, because Dr. Conley started explaining that I shouldn’t worry about how I looked, how everyone had something they didn’t like about their face. Why, he himself had had terrible acne as a teenager, and that had made him feel awful. Acne, was he serious? How could my problem actually be compared to acne? Any hope I’d allowed myself died right then” (154).

In some ways this surgeon’s attempt at empathy was more a reflection of the cliché ‘too little too late’ than anything, for nowhere in her memoir does Grealy speak of any substantive attempts at empathy from the long list of physicians she encountered. On the contrary, their

clinically oriented focus across the great divide of professional distance conveniently shielded them from that which she could not shield herself. Consequently, she suffered alone: “My despair worsened a few days later when I went to the library ... and secretly looked up books on plastic surgery ... To my eye, many of the people used as examples looked even worse afterward ... Was this what my life was going to be? I felt utterly without hope, completely alone and without any chance of ever being loved ... For the first time I wished I were dead” (155).

Simple acknowledgment and reassurance from this physician could have gone a long way in offsetting her suffering, but by Grealy’s account it was never forthcoming, never something she could rely upon. In exploring the chasm between doctors and patients, Rita Charon reveals stark perceptual differences between the two: “Doctors tend to consider the events of sickness rather narrowly as biological phenomena requiring medical or behavioral intervention, while patients tend to see illness within the frame and scope of their entire lives” (22). Nowhere is this difference more salient than when a patient’s illness is visible in the context of the outside world, as in Grealy’s case. And with this visibility comes “the emotions of shame, blame and fear: These emotions, among others, saturate illness and add immeasurably to the suffering it causes. Unless explicitly acknowledged and examined, these emotions and the suffering they cause can irrevocably separate doctor from patient, therefore preventing effective care” (22).

One could argue that Grealy’s physicians provided her with excellent care, for how could they offer redress to that which they didn’t know she was lacking or needing? Without her explicit narrative about the psychosocial effects of her disfigurement during the clinical encounter, they had no substantive information with which to make a proper assessment and thus offer solace or comfort. Unfortunately neither Grealy nor her mother provided the doctors with a complete rendering of the depths to which Grealy suffered, and in the end this omission irrevocably fractured the possibility of a successful doctor-patient relationship. As social psychologist Alan Radley states, “to display one’s suffering anew (and every meeting with another is a new context) is to display references that have not been established prior to that encounter. The mediation that will be employed and the properties that might be cross-referred do not lie inside the person who suffers, but are taken up in the context (the relationship, the setting) in which the meeting takes place” (Radley 2009).

Face to face

When two separate selves meet, two separate consciousnesses, an intersubjective exchange is created where

cognitive and perceptual experiences are interpreted through language—both verbal as well as body language. This language is in turn influenced by one’s temporal experiences, the biopsychosocial effects of the past, present, and proposed or hoped for future circumstances. In addition, multi-layered expectations at both conscious and unconscious levels come into play, all of which necessitate a steadfastness of intention and commitment if a mutually beneficial relationship is desired.

It is within this intersubjective realm where the singularity of the doctor-patient relationship rests, where the vagaries brought on by illness and the potential chronicity thereof significantly heighten the stakes of such intersubjectivity, for the disruption of one’s health and well-being and its accompanying fears and anxieties pose special requirements, obligations and demands that do not exist in other relationships. Thus, the challenges inherent in the textuality of this interchange, in the nuances and limitations found within language itself are multifaceted, and require address.

Levinas scholar Craig Irvine asserts that, “Language is the means by which the other, as Other, manifests itself as something more than just another object of comprehension, another object I could appropriate or identify. Language allows the terms to relate without making them neighbors—it ‘accomplishes a relation such that the terms are not limitrophe within this relation’ (Levinas 1969).

Levinas terms this mode of relation “face,” describing it as “exceeding *the idea of the other in me* ... The face brings a notion of truth which, in contradistinction to contemporary ontology, is not the disclosure of an impersonal Neuter, but *expression*: the existent breaks through all the envelopings and generalities of Being to spread out in its ‘form’ the totality of its ‘content,’ finally abolishing the distinction between form and content. This is not achieved by some sort of modification of the knowledge that thematizes, but precisely by ‘thematization’ turning into conversation ... the first content of expression is the expression itself. To approach the Other in conversation is to welcome his expression, in which at each instant he overflows the idea a thought would carry away from it. It is therefore to receive from the Other beyond the capacity of the I, which means exactly: to have the idea of infinity” (50–1).

Levinas aptly points to how ethics enters into this encounter, creating a relation of the highest order: “In the concrete the positive face of the formal structure, having the idea of infinity, is discourse, specified as an ethical relation...” (80). “For Levinas,” Irvine explains, “the priority of the Other is quintessentially manifest in my encounter with his suffering and death ... In the Other’s suffering, then, I face ‘the inevitable and preemptory ethical problem of the medication which is my duty.’ Indeed,

‘wherever a moan, a cry, a groan or a sigh happens, there is the original call for aid, for curative help, for help from the other ego whose alterity, whose exteriority promises salvation ... What lies on the other side of silence, a silence that envelops the suffering of the Other, is a call—in fact a demand ... It is a call so powerful, so fundamental, that ... To answer the call of the Other is to give one’s very self, for this answer is the very *essence* of the self” (Irvine 2005).

The ever-present mediation of language upon any interchange should always be a consideration, which brings us back to medical discourse and the power dynamic with which it is fraught. Not only does medical discourse assume an inequitable power base, philosopher Judith Butler shows us that narrative itself poses a myriad of tactical roadblocks: “the structure of address is not a feature of narrative, one of its many and variable attributes, but an interruption of narrative. The moment the story is addressed to someone, it assumes a rhetorical dimension that is not reducible to a narrative function. It presumes that someone, and it seeks to recruit and act upon that someone. Something is being done with language when the account that I give begins: it is invariably interlocutory, ghosted, laden, persuasive, and tactical. It may well seek to communicate a truth, but it can do this, if it can, only by exercising a relational dimension of language” (Butler 2005).

Contrary to the seemingly monadic nature of language and the dyadic resemblance of the doctor-patient interchange, Butler reminds us that the structure of address to the other is affected not by one element or even two, but by a multiplicity of mediating factors: “Our exchange is conditioned and mediated by language, by conventions, by a sedimentation of norms that are social in character and that exceed the perspective of those involved in the exchange” (28). She then leaves us with the inevitable query, “So how are we to understand the impersonal perspective by which our personal encounter is occasioned and disoriented?” Practicing intentionality of consciousness can certainly be an aid in what is otherwise always beyond our reach, for as Levinas shows us, “the other always eludes my grasp ... the Other remains infinitely transcendent, infinitely foreign; his face in which his epiphany is produced and which appeals to me breaks with the world that can be common to us, whose virtualities are inscribed in our *nature* and developed by our existence. Speech proceeds from absolute difference” (194).

Within this complex, multi-layered system of self and other in relationship, the question we are then left with is: how do we share a common world? Or perhaps more precisely, *do* we share a common world? The world with which Grealy was forced to inhabit shared little in common with others—so much so that she had no choice but to

create one of her own: “I lived vividly in my world of hospitals and animals and fantasy. I had no sense of myself in relation to the ‘normal’ people I walked by every day” (105). It is not surprising that her love of animals, especially horses, were a great comfort to her, however it could not make up for the void she experienced among her peers, or even within her own family. While home ill from the effects of chemotherapy, she describes the singularity of her experience, the cultivation of her aloneness: “The house itself mothered me. With everyone else away at school or at work, I somehow thought my eavesdropping created a new meaning for the clock, the hot water heater, the cats growling over their food. I felt that my listening made for them, and for myself, a real home. The house empty was a different place from the house occupied” (81).

It is interesting to note Grealy’s reference to “listening,” and its ability to make a “real home” for herself, for it was this type of listening that ironically neither her doctors nor her family were able to provide. And yet it is through the simple act of listening, of being present with another, of hearing not only the words but the spaces between the words, of hearing what the body is telling through its own language of gesture, gaze, form and function, that we give comfort and solace to another, that we reach out beyond the self toward the other in an act of communion, of recognizability, for it is through the mirror of the other that we come to know the self.

And yet who was Grealy’s mirror? Where was her source of recognition in a culture that defines beauty as an ideal and disfigurement as a source of shame and ridicule? Within this reverence for absolute beauty, and the denigration of anything that falls short of it, where does one go to find love and acceptance? Where does the search for truth and beauty begin, and where does it end? Certainly the quest for everlasting beauty is a consequence of growing up female in our Western culture, a culture where, had Grealy been male instead of female, perhaps her search would not have been so excessive, so obsessive, so exhaustive. Not only does deviation from accepted norms exact a harsher judgment and toll on women than it does men, it also weighs more heavily upon them due to the proliferation of feminine ideals in print media, as well as in subliminal advertising geared toward unrealistic and unattainable images of perfection.

The inequities of gender and the subsequent ridicule Grealy endured as a result of socially endorsed and expected images of the feminine ideal is voiced without malice when she writes about the insults men often hurled at her: “They weren’t thrown at me because I was disfigured, they were thrown at me because I was a disfigured woman ... Had I been a man, would I have had to walk down the street while a group of young women followed and denigrated my sexual worth (67)?

The relationship between gender and illness

Gendered constructions of medicine, health, family, even voice, are so entrenched in our Western culture we don't even think to question them, much less act upon them. And for the most part neither did Lucy Grealy, even when it came to the impact of gender on her own illness. Like other women, she fell into the familiar socio-cultural scripts that are readily accepted without much argument, for it is far easier to follow the norm than it is to stray, especially if we happen to have an illness which we cannot hide from the world, one which is visible in the most painful sense of the word. We greet the world with our face, our visage, but what do we do when the world turns its own face away? Where do we go then, and what do we do with that rejection?

Because we live in an American culture where sameness is valued and difference is feared, the ease with which we marginalize those who appear different from us is discrimination in its most insidious form. From the time we are infants, we are treated, dressed, even spoken to differently depending upon our gender, and whether male or female, each carries with it a set of implicit and explicit roles and expectations complete with a set of rewards and reinforcements that are dangled in front of us like precious jewels. Rites of passage are marked by gendered associations with body or social status: getting a first bra, winning a place on the cheerleading team—both of which are predicated upon culturally scripted feminine norms of beauty and acceptance.

In her essay "Carnal Acts," Nancy Mairs describes her own experience of what the feminine ideal meant to her as a young woman: "I was never a beautiful woman, and for that reason I've spent most of my life (together with probably at least 95 percent of the female population in the United States) suffering from the shame of falling short of an unattainable standard. The ideal woman of my generation was ... perky, I think you'd say, rather than gorgeous. Blond hair pulled into a bouncing ponytail. Wide blue eyes, turned-up nose with maybe a scattering of gold freckles across it, a small mouth with full lips over straight white teeth. Her breasts were large but well harnessed high on her chest; her tiny waist flared to hips just wide enough to give the crinolines under her circle skirt a starting outward push. In terms of personality, she was outgoing, even bubbly, not pensive or mysterious. Her milieu was the front fender of a while Corvette convertible, surrounded by teasing crew-cuts, dressed in black flats, a sissy blouse, and the letter sweater of the Corvette owner. Needless to say, she never missed a prom" (Mairs 1991).

Ten years later, Mairs experienced the first symptoms of Multiple Sclerosis, which were rather mild at first and at a time when, she says, she felt she looked her best. "Not

beautiful still, but the ideal had shifted enough so that my flat chest and narrow hips gave me an elegantly attenuated shape, set off by a thick mass of long, straight, shining hair. I had terrific legs, long and shapely ... Not surprisingly, I suppose, during this time I involved myself in several pretty torrid love affairs" (273). But then the progression of the disease began demanding more and more life adjustments from her: first the need for a cane, then a leg brace, and then a three-wheeled electric scooter. This decline in her body's abilities signaled other changes as well, not the least of which was having a body that was now "weakened and mis-shapen by disease" (275).

Giving voice to the effect this has had on her self image, her sexuality, her life, she compares her present self to her past self: "My self esteem diminishes further as age and illness strip from me the features that made me, for a brief while anyway, a good-looking, even sexy, young woman. No more long, bounding strides: I shuffle along with the timid gait I remember observing, with pity and impatience, in the little old ladies at Boston's Symphony Hall on Friday afternoons. No more lithe, girlish figure: My belly sags from the loss of muscle tone, which also creates all kinds of intestinal disruptions, hopelessly humiliating in a society in which excretory functions remain strictly unspeakable. No more sex either, if society had its way. The sexuality of the disabled so repulses most people that you can hardly get a doctor, let alone a member of the general population, to consider the issues it raises. Cripples simply aren't supposed to Want It, much less Do It. Fortunately, I've got a husband with a strong libido and a weak sense of social propriety, or else I'd find myself perforce practicing a vow of chastity I never cared to take" (275).

Unlike Mairs, Grealy never married, which adds yet another layer to the gendered nature of illness, for women in Western culture are expected to "grow up and get married." The stigma of everlasting single hood exists even without illness, but when illness is attached to an already single status, the equation only serves to exacerbate difficult life issues involving financial security, independent versus dependent living options, and the even greater stigma that comes from concomitant feelings of loneliness and isolation, which Grealy speaks to throughout her memoir.

While men in Western culture can certainly face similar issues regarding marital status and levels of physical attractiveness, the socio-cultural pressure to be married and present an attractive face and physique to the world is indeed much greater for women than it is for men, and this dichotomy is as true in the current millennium as it was in prior centuries. As much as the feminist movement did to pave the way for women's equality in a patriarchal society, it also cast a shadow over the human need for the other, nurturing our culture's reverence for a fiercely held

independence that is valued almost as much as beauty. The result is that we try to escape the silent judgments and sideways glances by tending to the wounds of loneliness behind closed doors, drawing the shades so no one will see the ache or hear the loss, not even ourselves. As clinical psychologist Gershen Kaufman points out in his book, *Shame, The Power of Caring*, “The paradox about shame is that there is shame about shame” (Kaufman 1985).

Unfortunately, Grealy did not have the benefit of a loving, live-in support system like Mairs, which over time only deepened her emotional pain and anguish, confirming her belief that the reason she was alone was because of her facial deformity, what she saw as her “ugliness.” As Grealy writes, “At times I was so lonely I was amazed I didn’t just expire right there on the spot, as if loneliness that strong were a divine thunderbolt that could strike me down at any moment, whether I was in bed, at a crowded dinner table, or at an empty roadside stop” (206).

Caught in a self-defeating cycle perpetuated by the dictates of gendered socio-cultural constructs from which there was no reprieve, Grealy did the only thing she could do: utilized her writing as a balm to soothe the pain. And though her ability to write about her loneliness is a tribute to her strength, it does not negate gender’s impact on illness, nor does it negate the human need for connection, for recognition, for someone to love and care for us. And in the realm of medicine, within the sacredness of the clinical encounter, this is nothing less than an ethical responsibility.

As Levinas points out in his objective for *Totality and Infinity*, “The establishing of this primacy of the ethical, that is, of the relationship of man to man—signification, teaching, and justice—a primacy of an irreducible structure upon which all the other structures rest...” (79). And so it is here, within this irreducible structure, the juncture where self and other meet in the clinical encounter, that we risk exposing ourselves, that we venture a thousand layers deep into our nakedness, our vulnerability, our pain, hoping beyond hope that in so doing, our search will be over and we will find our place in the world, a place to belong where we are loved and accepted for the unique individuals we are, and not for who we “should be” under some artificially prescribed notion of gender derived from archaic social constructions.

The simplistic duality of either/or reductionism, where one is either pretty or ugly, smart or dumb, rich or poor, names us as “less than,” or “not good enough” before we ever have a chance to explore who we really are beyond such compartmentalized trappings. Grealy unfortunately suffered not only from a cancer that rendered her physically deformed, but moreover, from a multitude of socially constructed edicts that unnecessarily exacerbated the effects of her illness. From the cold distance she experienced in the clinical encounter to the gendered nature of illness and disability in our society, each systematically

negated any chance she otherwise might have had to develop a self independent of such dominant and influential strangleholds.

Conclusion

Lucy Grealy’s memoir, *Autobiography of a Face*, provides the reader with a coming of age story within the medical context, and the socio-cultural lens through which we view her narrative never fails to remind us of the significance of context, and the resulting cultural constructs from which we define ourselves. Once we recognize the covert ways in which familial and socio-cultural contexts govern and mediate our very thoughts, actions and behaviors, we begin to understand their insidious nature.

Perhaps we as a society can learn from Grealy’s pain and loss, and work toward an ethical responsibility for the Other that Levinas steadfastly purports, for in a society more concerned with superficiality than genuineness, with form rather than substance, it would prove to be no less than a triumph, and no more than an act of humility.

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