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How the Internet Saved My Daughter and How Social Media Saved My Family

By Marc Santos

Preface

This installation is a personal and cathartic engagement with my initial inability to cope with my daughter's cancer. [Note P] It details events that began in August of 2008 and concluded, in a sense, in February of 2009. I offer it with hopes of helping digitally-oriented Rhetoric and Composition scholars "determine a should for a we" (Patricia Sullivan & James E. Porter, 1997, p. 103). How should we approach pedagogy in the early 21st century? My tentative answer is to approach it less with aims of "constructing knowledge" and more with hopes of "negotiating encounters."

Given my suspicion toward traditional forms of rationality, this project, I hope, represents what Sullivan and Porter describe as feminist research in *Opening Spaces*. This is my first extended attempt to think through my own experiences and transformation. I share this engagement with you because I think it helps me theorize a dimension of rhetorical encounter preceding consciousness or knowledge production. Later in the project, I term this dimension "rhetorical support"--implicitly echoing Burke's Paradox of Substance--as the dimension upon which Being (be it identity, community, ideology, narrative) emerges. A digital-pedagogic practice dedicated to rhetorical support would embrace equally alongside knowledge values such as humility, courage, and risk.

I explicitly draw upon the work of Jim Corder and, to a lesser extent, Emmanuel Levinas. Both speak to the dialogic potential of 21st century technologies, offering us robust theories that emphasize the human need for, and potential disruption caused by, others and their narratives. I want to use these theories, and my own traumatic experiences--what Corder will identify as challenges to my narrative--to question what is fast becoming a commonplace among digital humanists: that social media sites, particularly Facebook, are fueled by and further fuel humanity's worst narcissistic tendencies. Where this critique locates narcissicism as a cause, I will instead argue that digital technologies might awaken desire for something missing from atomistic Modern life; they rekindle a desire for others. What might appear as narciccism could be attending to the abyss, and a new, distributed form of loquacious huddling.

Our Story

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August 8th 2008. I remember spending most of the morning deliberating what kind of shoes to buy. My wife, one year-old daughter, and I had just moved to Tampa, FL; I was preparing to start my new job with the University of South Florida. I considered new shoes an important part of my pending professional preparatory process. My quiet time with coffee, computer, and images of shoes (and, after shoes, ice cream, for Rowan's sake, of course), was interrupted by my wife hysterically running at me, shaking her computer and yelling "LOOK AT THIS!!!"

"This" was a link to a website on retinoblastoma, including a picture of white-eye reflex.

Some back story here: for a little more than a week Meg had noticed that Rowan's left eye was slightly changing color from a light blue to a sea green. As first-time parents, we weren't sure if this was normal (it wasn't covered in the manual), so Meg posted a question to her Babyfit.com group, a social network putting parents-to-be in contact with other expecting parents sharing a similar due date. It seemed that other parents had not experienced spontaneous eye color change, and requested a picture. As you can see what is distinctive about the photograph is the "white-eye reflex" instead of the more typical red-eye reflex. Meg and I had noticed this once or twice before in Rowan's pictures, but dismissed it as an odd reflection (and the Internet will tell you it is an odd reflection about 99% of the time). One mom, Madeline Robb from Manchester, England, noticed the picture and remembered an acquaintance's ordeal years earlier. Specifically, she remembered how white-eye reflex can be in rare cases a sign of a serious medical problem. She did an Internet search and reluctantly sent us the email and link appearing on the next screen.

> Hey Megan
>
> It must be so hot there right now! I've spent two full summers in that Florida heat and humidity.. ah!
>
> How is the process of settling in going?
>
> You and Rowan are looking great!
>
> I just noticed something - Rowan's left eye is reflecting in some of her pictures (esp the ones where she's in her pink t-shirt).
>
> The reason I'm writing this is because an acquaintance of ours noticed the same thing in the pictures of their child and it was found to be serious.
>
> Don't panic, I just wanted to suggest that you have her checked by an optometrist from the experience our acquaintances had with their child.

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> I'm not saying it definitely IS anything but she's such a precious girl I had to mention it.
>
> Here is a link to something - but before you look - I'm not trying to scare you. http://tinyurl.com/yg4pld Keep me posted! Maddie x

What is interesting here, particularly in light of where this presentation will end, is Madeline's hesitancy to send the link. She didn't really know us at all, and she was sincerely concerned to cause us undue panic. In interviews with *Inside Edition*, *Reader's Digest*, *US Today* and other publications, Madeline consistently references the difficulty she faced in composing this email. [Note 1] We can read it, too. The phatic and tense introductory lines seeking to form some trace of identification, the awkward and impossible transition, the repeated avoidance of certitude. But, fortunately, courageously, miraculously she did send the link.

Which brings us back to the grumpy husband, the hysterical wife, and the shaking laptop.

My immediate response (likely ironic to anyone familiar with my research agenda) was "are you going to trust everything you read on the Internet?" I was annoyed. Not because my daughter might have some long, impossible-to-pronounce disease. I knew my daughter was fine. I was annoyed because I knew my morning of shoes and ice cream was about to be suffocated by an unnecessary trip to the doctor's office.

I WAS WRONG.

100 miles, 13 hours, 3 doctors, one MRI and one Cat Scan later we learned that our daughter had retinoblastoma, an extremely aggressive and dangerous form of eye cancer. 3 days, 300 miles, 1 hurricane, and 1 exam under anesthesia later, we learned that we were very fortunate that her cancer was unilateral rather than bilateral. We learned that she would likely never again see out of her left eye. We learned that we would have to decide whether to subject her to radiation treatment in an attempt to save the eye. We learned that she would have to undergo 6 months of extensive chemotherapy. We learned that, even if she beat retinoblastoma, she would be at an extremely high risk to develop another form of cancer in childhood or adolescence. We learned that the tumor, undiagnosed at her 3, 6, and 9 month pediatric checkups was likely present since birth and had grown to occupy almost 80% of her eye. We learned that retinoblastoma almost exclusively affects children. We learned that, because retinoblastoma affects so few children every year, most pediatricians do not bother to actually check eyes in a dark room (the only method of early detection).

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We learned that, had we waited another 2 months until her 12 month checkup, Rowan's tumor would have in all probability spread cells outside of her eye, onto her brainstem, and into her brain. Had those cells spread, she would have most certainly died.

Literally, the Internet saved my daughter's life.

Rhetorical Support

As my title suggests, when I first began reflecting on my family's story, I could only think of it in terms of providing the Internet some good press. This is how our story was packaged and dispensed across mainstream and Internet news outlets (and it still gets some attention-- *Reader's Digest Canada* will be running the story in June of 2010--almost two full years later). Given that the Web 2.0 honeymoon is pretty much over (both in the mainstream and in academia), the ole Internets could use some good press.

When I say that the honeymoon is over, I am thinking of three primary assaults on Web 2.0 / social media / the ole Internets. First, there is the Foucault/Hardt and Negri inspired work of theorists such as David Golumbia (in *The Cultural Logic of Computation*) or Alexander Gallaway and Eugene Thacker (in *The Exploit*). These materialist theorists position network technologies as radically extending and diffusing forms of hierarchy and control and further entrenching capitalist and conservative values. Rather than producing democracy, such diffusion and entrenching actually hinder the possibility for resistance. Second, there is the work of Nicholas Carr (2008), who intelligently extends the early hyperbolic rantings of Andrew Keen. Summarized bluntly, Carr argues that the Internet makes us stupider by eroding attention span and overwhelming memory. Third, there is the work of Jean M. Twenge and W. Keith Campbell, William Deresiewicz, and others on the Internet's amplification of narcissism, particularly among young adults. I believe such critical work is important; all three remind us that the Internet is not a ubiquitous good. While I think my story suggests a response to all three of these dispositions, I by and large will limit myself in this work to confronting the third (though I will address Carr briefly; given the sophistication of their work, I will not attempt a direct response at Golumbia, Gallaway, or Thacker here). I will urge Rhetoric and Composition scholars (a we) to take an investment in determining how these new technologies will determine us (a should).

My thesis might be reduced to: because social media technologies expose and facilitate intersubjective relationships, we should invest ourselves in fostering relationships, rather than with persuading audiences or constructing knowledges. This means encouraging participating, rather than merely encouraging knowing, thinking, or even--as many theories of new media do--producing.

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As a coda to Rowan's story, I would point out that at least 3 other children have been diagnosed thanks to our story's mass broadcast. The Internet makes it easier to pay it forward.

Certainly our story lends credence to what terms such as "noble amateur" or "flattened infoscape" really mean. Few are arguing that social media are going to allow Madeline the stay-at-home-mom to epistemically contribute to the cure for cancer. Research of that nature will continue to be conducted by an exclusive, well-supported, institutionally-validated, few. But social media do exponentially engage many in sharing the products of those elite few. Anyone familiar with Steven Johnson or Clay Shirky understands that this is what we mean by an increasingly smarter 21st century American populace. Knowledge construction might not be necessarily more egalitarian or democratic, but knowledge distribution certainly is.

In regards to Carr's arguments, I would note that he relies on particular, individualistic measures of intelligence--and he treats these measures as universally "good." I would assert that Carr worries over individuals getting stupider because he doesn't have the disciplinary apparatus necessary to acknowledge that a body can be smart. Nor does he seem open to the idea that the forms of intelligence he chooses to highlight might in fact be a production of literacy and print mediums, and quite inessential (in every sense of the word), to human progress or happiness.

In some ways, then, it reminds me of rhetoric's ancient battle--it is Socrates and Callicles all over again--one emphasizing the intellect of the individual [mind], one speaking to necessity of the mass [body]. [Note 2] In articulating a theory for 21st century digital Rhetoric and Composition, I am looking to intertwine these two positions--to make the individual mind a responsible (and responsive) agent embedded within the social body.

The impact social media had upon my family doesn't necessarily end with diagnosing Rowan's cancer; its is not exhausted in the *knowing* about the cancer; it extends to how it provided us with emotional, and what I want to term rhetorical, support. My story suggests how one particular techno-social Internet practice, social media and social networking, is transforming both the ways in which our stories shape us (emphasis on the quantity of the "our") and the ways in which our mass presence transforms our psycho-social reliance on stories. The definition of rhetorical support worked out here will draw upon and extend Jim Corder's (1985) exploration of narrative in his essay "Argument as Emergence, Rhetoric as Love" through a (albeit brief) discussion of Emmanuel Levinas's notion of asymmetrical intersubjectivty.

For Corder, all individual's "narrate" a story that locates them within the fabric of space and time. Rhetoric supports and facilitates consciousness; rhetorical narratives provide a frame of reference for understanding and navigating the world.

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The interruption of one's narrative disorients the subject, and requires revision. Rhetoric, for Corder, becomes a willingness to change one's narrative; when confronted by a distressing narrative, a rhetorical subject learns to turn inward ("why don't I believe that") rather than outward ("how can you believe that?"). Here I would point to Julia Kristeva's (1991) conclusion in her recent *Strangers to Ourselves*:

> To worry or to smile, such is the choice when we are assailed by the strange; our decision depends on how familiar we are with our own ghosts. (p. 191)

Levinas's asymmetrical intersubjective ethics suggest that Corder's narration is not necessarily a conscious operation, rather it is extra-conscious activity that lays the ground from which consciousness emerges. Furthermore, I would argue that social media mean thatwe no longer individually narrate stories. Today's technology allows for a sense of self emanating from our networked existence with others: the linear plot is replaced by the matriced assemblage (in that our lives come to be understood less in terms of a "where-have-I-been-and-where-will-I-go?" and more in terms of "who-am-I-[with]").

I am advocating an approach to digital rhetoric not framed strictly as consciously directed, linear transference of episteme between two autonomous and fully-formed subjects. Rather, I urge attending to how particularly social media encounters, always affective and epistemic, contribute to and complicate subject formation and social relations. Living with others is hard work. There is no reason why it can't be hard, scholarly work.

In Corder's terms, I am approaching rhetoric as a willingness to revise one's own orientation rather than as a preoccupation with manipulating an other's narrative. The former approach conjures monikers such as "persuasion, argument, and antagonism." The latter I would associate with terms such as preontological, ethical, and agonism.

In theorizing rhetorical support, I am looking to extend Corder's conscious disposition toward change into a theory of a kind of change that precedes consciousness. I am reading Corder's work through the phenomenological, metaphysical ethics of Emmanuel Levinas(1969) and Alphonso Lingis (1994). In short, Levinas's ethics stress our debt to alterity for the very formation of our existence; this debt charges us with an infinite responsibility for others. These intersubjective ethics are asymmetrical because I cannot assume that I construct the other as she constructs me--I always owe more than I have to give. The other changes me before a (conscious, thinking, responsive) "I" ever emerges on the scene to make any kind of "sense."

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I am born from an irrecoverable affective engagement with others. That the relation is irrecoverable is why, like Burke's abyss, it potentially haunts me. Thus, Levinas asks us to attend to all others rather than to bury ourselves deeper into our symbol systems. In terms more familiar to rhetoric, to welcome them rather than persuade them (or, as Victor Vitanza might write, to ontologize, categorize, and hence "kNOw them"). I hope those familiar with D. Diane Davis' project for a "non-appropriative rhetoric" will see connections here since like Davis I am interested in tracking down a dimension of rhetoric not immediately reducible to meaning-making (Davis, 2005, pp. 191-192), or, in light of Vitanza, reducing others to categorical meanings.

My experiences with my daughter's cancer and with social media have oriented me away from a primary interest in what a consciousness does with rhetoric and toward an interest in what rhetoric does with consciousness. It is on the basis of this change in interest that I advocate for a rhetorical-ethics more attuned to attending to others than to explicitly (or intentionally) changing them. Building off of Levinas, we cannot help, by our very presence, to disturb and thus change an other. We can, however, develop a rhetorical-digital-compositional-ethical practice that takes such change into account. Drawn from Madeline's email, my theory of rhetorical support aims to suggest a praxis informed by a delicate balance between courage, humility, and knowledge. We can think here of Wikipedia's contradictory mantra: "Be bold ...but please be careful."

Intersubjectivist ethics go beyond notions of discourse community. Its not just about people getting together to construct knowledge. It is a further recognition that getting together (re)produces identity or challenges it, depending on the scene and the tenor of the interlocutors. Before we make knowledge, we have to make each other. And, I'll suggest, the willingness to contact an other requires a very particular courage. [Note 3]

Cancer, Loss, Change

I frankly admit that I haven't done any traditional research into coping with cancer. I hope that my experiences here are fairly representative. Cancer infects every aspect of one's life. While dealing with Rowan's cancer, even everyday tasks became difficult. I never knew when the cancer would find me. I remember standing in a grocery store in Miami looking for string cheese and just losing it in the dairy isle. Of course, I wasn't simply losing it. I was losing me. Because, especially in those early months when we couldn't know whether the cancer would spread out of Rowan's eye, nothing felt normal and we never felt ourselves. Of course, one can point to the context and rightly say that nothing was normal. But more than that, I would theorize that we were no longer ourselves. Cancer, and its specter of impending death, forced upon us the need for a completely new narrative, and hence, had engendered the emergence of new people. I am still getting to know me. To this day

my wife will often say "I still don't feel myself." I know the feeling. It is likely tied to a resistance to accept what we have become even as we know we are transforming.

In *Breaking Up [at] Totality*, D. Diane Davis (2005) points toward the kairotic laughter that laughs us as an indication of the beyond-consciousness underlying our self-knowledge (see particularly 21-24). Recalling an inability to stop laughing in church, Davis writes:

> My whole Being wants desperately ***NOT*** to laugh, and yet it's clear to me that my will is not in control. [...] I fight desperately for control. But to no avail. My body has been *possessed* by the force of laughter: Despite my reason and my will, laughter BURSTS out. The battle is over: "I" have been conquered. (p. 22)

I would contribute to this theory by noting that affective displacement can emerge as laugh or tear. Davis describes a singular kairotic moment in which we temporarily lose ourselves. I hope, in this section, to describe something of a different duration.

My experience confirms my inclinations toward fluid notions of identity. Cancer isn't something that happens to a self, its something that transforms it. For evidence of the extent to which cancer forms a "new" person, I would turn to the divorce rate among retinoblastoma families. One of the first things you are told after diagnosis is that couples enduring a child with retinoblastoma have an 80% divorce rate. No doubt much of this can be attributed to the situation's high emotional stakes and the illness's high mortality rate. But also, I would suggest, it is because after a trauma of this magnitude the person you are isn't any longer the person your spouse chose to marry. And all that trauma, emotion, and loss don't make for the best conditions for a new courtship.

First-time parents are likely familiar with a degree of this *unheimlich*, this feeling of displacement, this interruption. But from the moment of our birth, culture, family, and institutions prepare us for and supply us with material to support such a "normal" transformation. There is no such support for childhood cancer. Hence my wife and I's *unheimlich*--we were/are an other to ourselves. As a successful white male, this is my first experience as really being anything other than "normal."

The difficulty of dealing with cancer's transformations is very caught up in our expectation for particular cultural, familial, and institutional narratives. In our case, the anticipation of what should have been the narrative of Rowan's life. Even though, over one year removed from her last chemotherapy session, her cancer is in complete remission and her right eye shows no seeds, we still live in constant fear. Rowan's future will include a steady diet of exams under anesthesia and MRI's. Furthermore, retinoblastoma is an indicator of a disposition toward cancer. We will

spend the rest of her life, in essence, waiting for cancer to return. The traditional narratives of her first car, graduating high school, going off to college, getting married and having children are/will be/will-have-been haunted by the most horrible of possibilities and memories.

Fortunately, this is not a transformation that Rowan has to endure, although her childhood will certainly involve different narratives than those of the children around her. Her story promises to be more of difference than of loss. Not so for my wife and I. We lost our "normalcy." We lost the comfort of rhetorical support. We lost our selves. [Note 4]

Thanks to social media, my wife and I did not, and do not, have to undergo this transformation alone. In addition to a supporting family, and good friends, the few face-to-face encounters we had during treatments with other parents, and Meg and Rowan's Tuesday visits to Tampa's exemplary Children's Cancer Center, we had social media putting us in contact with other families coping with retinoblastoma, childhood cancer, and the terrible transformations they engender. In the face of such uncertainty, we wanted others to help validate and construct our new life's narrative. In the process, the narrative of our lives (and the specter of bleak endings) becomes enmeshed in a network of altered narratives, to the extent that being-in-network operates alongside (and perhaps overrides) the linear-teleologic imagining of coming-to-be. It is through this alongside that I began to sense that perhaps we didn't need to craft a new narrative as much as we needed to find a new network. In all likelihood, it's both: a new narrative within a new network. Social media help facilitate both.

Social media offered rhetorical support by providing us with material to remix into our new story. It also provided us with people to affirm this story. It provided a venue for sharing: complaints about doctors, hospital bureaucracy, fears, frustrations (particularly about meeting a child just in time to learn they will die), loss, the difficulty of rotating a prosthetic eye (my wife and I can actually "one-time" this problem now--talk about the abject transforming into the mundane), hope, hopelessness, detachment, victories, remissions, celebrations, and milestones.

More important than the content of our sharing, it also let us share ears; it let us simply be there to "say." In *The Community of Those Who Have Nothing in Common*, Alphonso Lingis (1994) speaks to the impossibility of visiting the bedside of a dying parent. Particularly, playing with echoes of Levinas's distinction between the said and the saying (the ontological and the ethical), Lingis notes that we often come to find ourselves, in this moment-before-death-that-calls-for-something-to-be-said, with absolutely nothing to say. But, he argues:

> What is imperative is that you be there and speak; what you say, in the end, hardly matters (p. 108).

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So, too, with the retinoblastoma community. Social media provide(d) us, as parents, with the ability to say. Another sharing amongst this community is the commonplace discussion of friendship--every parent has the story of good friends who simply disappear after diagnosis. The disappearance of many friends who simply could not imagine what could be said, and therefore offered no saying. Of course, there is also the rise of other acquaintances into friends, who perhaps understood the futility of whatever they said but also recognized the importance of an attending ear. Those people know who they are. We thank them.

To recognize the difference between the saying and the said is to unsettle our (and I mean this broadly to include most who dwell within institution's of higher learning) disposition toward content/knowledge. The said falls within the realms of the ontological, the hermeneutic, the epistemological. The saying, however, attempts to capture something more primal and elusive. In place of the (said) content of a communicative utterance, attention to the saying seeks to interpret the significance of the unsignified performance of an utterance. It is through saying, I believe, that we nourish our sense of place within the infinity of space. And new ways of saying (new technologies) likely reveal to us other orientations toward saids (and highlight the peculiarities of our ways of saying).

I wouldn't argue that such support is necessarily "consensus" and later in this installation I will address a particularly charged conflict within the community. Nor am I speaking for the Internet here as a mass many-to-many communicative technology as much as I am speaking of social media, which I would like to frame as a particular one-to-group-and-back-again communicative technology. Its not here comes everybody all at once. Social media are not groups of everybody, rather they enable groups of particular people. One of social media's most unique properties is its ability to put us into proximity with others--to allow both patient thinking and immediate response. [Note 5]

Nor would I argue that all rhetorical support is necessarily good in a strictly moral sense. As many recent critics of social media have pointed out, these technologies and practices can just as easily support terrorism, fascism, oppression, or hate as they can justice, democracy, liberation, or love. But I would argue that such technologies open the possibility for "goodness" and ethics in a pre-moral, ontological, ethical, rhetorically-supportive sense. At least they're hating together. My precise interest isn't in the hate of course, but in the potential to come together in new ways, if only because coming into contact, coming together, has the potential to help break us apart. Recalling Kristeva, the reaction to breaking apart can be humility or anger, love or hate. We, as instructors in Rhetoric and Composition and Communication--as scholars across the humanities--have to invest our time, passion, and energy into helping determine how our technologies will determine us.

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I want to suggest that social media isn't necessarily bound to the binaries informing Walter Ong's (1986) secondary orality; it is not simply a matter of either the ear or the eye. To a culture so grounded in the ontological distance instigated by Ong/McLuhan's literacy/print (the eye), it might initially seem that this is a reincorporation of the values Ong, Havelock, and others have associated with cultures of the ear. I want to go a step farther, however, and propose that--especially given the "distance" amplified by literacy and print, the primary sensibility of social media is *touch*. Sensibility here is Levinas's term and I use it to suggests an affective, bodily thinking that precedes conscious thought. In proximity to an other's response, we feel them. Their difference touches us at a level "below" the skin and under-our-thought. Rhetorical support is an acknowledgement that words are a pathetic extension of our hands, they can approach as fists (Kenneth Burke, 1984, *Permanence and Change,* pp. 191-192) or in the form of caress (Levinas, 1969, *Totality and Infinity,* pp. 257-258). While they always threaten with violence, we can temper that threat through a willingness to re-orient the self rather than change the other. This is particularly the kind of determinism I believe Rhetoric and Composition scholars can encourage for technology. Once again: courage, humility, knowledge, and, as Madeline's email emphasizes, risk.

I want to posit my experience with cancer as a hyper-amplification of a basic human condition: a need for others in the face of others. Others as the medium for a sense of belonging and home. Others as the catalyst for first thinking and recognizing ourselves. To manipulate Bill Readings: "Others [and not thought] necessarily as an addiction from which we never get free" (see *University in Ruins,* p. 128). Incorporating touching others to the thinking of thought. Others as a catalyst for thought and thinking; especially a rethinking of the self (as foundational Western concept) by a self (a collection of thoughts put in motion by the stirring of an other). In my particular case, being-with-death might have been the catalyst for a subjective reformation, but others were an indispensible part of the reconstitution responsible for the new me. And it is the technological and social transformations opened up by social media that facilitated this transformation.

Baseball Cards

It is precisely how social media intensify the addiction to others that some find so troubling, particularly those who's ontological-subjective narrative comes from traditional liberal Humanist senses shaped (dare I say determined) by literate and print narratives (especially the Great Canonical ones). [Note 6] I offer as example William Deresiewicz's (2009) recent Chronicle essay "Faux Friendship," which laments how Facebook displays the disfigured "fluid and flexible" (and thus empty and meaningless) state of contemporary friendship (and, by extension, postmodern subjectivity). He writes of his quantified friend list:

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> They're simulacra of my friends, little dehydrated packets of images and information, no more my friends than a set of baseball cards is the New York Mets.

The metaphor of childish toys (and childish relationships) also operates in his conclusion that:

> Friendship is devolving, in other words, from a relationship to a feeling, from something people share to something each of us hugs privately to ourselves in the loneliness of our electronic caves, rearranging the tokens of connection like a lonely child playing with dolls.

My first, tongue-in-cheek response here is to remind Deresiewicz that Plato and Aristotle, Byron and Emerson, can be baseball cards too: symbols frozen in time that, through their very distance from the present place and time, offer notions of a better, richer world. This once again rehashes the ancient debates between Idealism and sophistry, conjuring the ghosts of Socrates and Callicles. Such is not my explicit purpose here.

Instead, let me agree with Deresiewicz that we do turn to social media for subjective affirmation, that we are in his words "hoping that someone, anyone, will confirm our existence by answering back." But let's not sound too quickly the battle cry of narcissism. Let me argue that answering back--one to group and back again--is the unique power of social media. And let me argue that it both intensifies the call for and makes possible the realization of confirmation impossible in an atomistic, Modern age. Further, all that chattering predisposes us to the tentative nature of the narratives upon which we emerge(d) and through which we are sustained. Sharing the ephemeral--our edges--is what helps define us to each other and, more importantly, to ourselves. There's an underlying psycho-social reason why many of us feel the need to share intimate details with groups of friends--reasons that don't amount to self-infatuation. Status posts describing coffee grinds in the fridge, remarking on the tea in Kentucky, exploring "what Lost character am I?" critiquing the sexist speech of telemarketers, or hailing the rediscovery of AC/DC aren't necessarily extensions of a childhood verse "I am special. Look at me" (to quote off the flap of Twenge and Campbell's hyperbolic *The Narcissism Epidemic*). Perhaps they are really a lone sonar ping searching, hoping, for confirmation.

Recognizing what was once considered foundational as perhaps only chatter tends to ramp up disequilibrium. As Deresiewicz himself notes, echoing Foucault, the institutions of the 19th and 20th century, church, state, school, so central not only to subject formation but also to subjects maintaining (after all subjectivity is not an isolated event but rather enacted patterns of performativity), these institutions have lost much of their cultural hegemony. Add to the list of emaciated discursive

institutions the literary canon and even the television network (Oh Andy Griffith, oh Cosbys, oh Simpsons, where have you all gone?). Today, I choose my identity from more than three channels. Given both the volume and diversity of the cultural cacophony, we are left evermore loquacious over a seemingly expanding abyss. We can talk ourselves both to *and* from its edge. It's a matter of choice and perspective. I think my story has likely cemented both for me. How about you?

For one doesn't have to have coped with a child's cancer to see the foundations of the Self, instituted by thousands of years of literacy and print, coming to be questioned through new media practices.

I am reminded of Michael Feehan's (1985) anecdote from Kenneth Burke's visit to the University of Texas, Arlington:

> KB to The Scholar (offhandedly): What do you believe in?
> The Scholar to KB (leaning forward): What do you believe in?
> KB to The Scholar (impishly grinning): I believe in asking people what they believe in (p. 148).

Perhaps it would better to ask *who* we believe in. Perhaps more than asking others to expose themselves, we should seek others as a way of asking and exposing our self. And these subtle differences might best express the difference between Burke and Levinas's projects. Both, however, call upon us to dialogically engage the other from a position of ethical weakness (its turtles others all the way down, after all) rather than ontological, epistemological, or Canonical strength.

Our baseball cards form the house of cards (the institution, Foucault might say), from within which we think, work, and live. They trace the line of others (or lead to others, if we think in terms of disciplinary associations) that sketch the boundaries of my self. I think this installation makes it clear who I identify as my house of cards--Burke and Levinas, Corder and Davis, Sullivan and Porter. No doubt I have forgotten others. But to accept intersubjective ethics is to attempt to articulate to whom you are indebted and to invite others to show you how you might be indebted otherwise.

Against Deresiewicz and his liberal humanist baseball cards, I would assert that the need for validation is not new--even if since Socrates the need for validation has been castigated as weakness. What is new are the tools and sources for validation. What to the liberal humanist will always appear as narcissism and exhibitionism, I offer as a manifestation of social uncertainty and the need for others, in the face of such uncertainty, to confirm our existence. I understand my own experiences with cancer as an intensification of the 21st century condition, in which the legitimation crisis has spread from social institutions to the members of society. Such an amplification should not be described either euphorically or fatalistically (and I

recognize that I often border on euphoria, I read, listen, and face people such as Deresiewicz, Carr, Golumbia, Thacker and Gallaway precisely in an effort to temper my enthusiasm). I would encourage eschewing dramatic optimism or pessimism. It is transformative. It is change. It is disorienting. It calls for a rhetoric of cooperation, one that aims to change the self and help the other (rather than helping the self by changing the other).

A rhetoric of cooperation predicated on the necessity, for each subject, of rhetorical support. This is not mourning a loss of autonomy as much as an encouraging of togetherness. My theory: we tend to be more cooperative once we recognize we need support.

Coming Home (to a House of Cards)

I opened this installation with a narrative and, given my investment in the ways social media promote, incite, encourage, and challenge subjective narrativity, and my attachment of Sullivan and Porter's feminist ethics, I feel compelled to close with another.

As I mention earlier, the uniqueness of my family's story led to its mass broadcast; we were featured in countless print, television, and Internet news stories and effectively achieved our 15 minutes of fame. Given this, it wasn't unusual for us to get phone calls from people all over the country. One phone call in particular struck me. A mother, likely in her late 40's or early 50's from the sound of her voice, called to reassure us regarding our decision to enucleate. She wanted to let us know that Rowan could live to have a healthy, normal life. She had made the same decision over 20 years ago, and her daughter, now 25, had enjoyed a normal childhood. She was particularly proud that she was a soccer player.

I should break here, for some context: as I mentioned earlier the retinoblastoma community is not a homogenized collective. Like any group, its contours flow around its internal controversies. In retinoblastoma groups, one of the most intense controversies concerns how aggressively to fight to save an eye. Such a decision concerns a number of factors: the location of the tumor, whether the cancer has presented unilaterally or bilaterally, whether to use dangerous but often effective localized radiation treatments. Given the extent of Rowan's tumor, this really wasn't a question for Meg and I--we both immediately agreed that the eye had to go. Just hearing about different kinds of treatment can lead to passionate arguments or cause people to leave the group. No one is comfortable questioning their child's care. But many cases are not so clear. And many parents struggle with the body-issue decision to de-normalize their child.

I don't know the particular circumstances that surround the mother who talked with me on the phone that day. But I realized, as she fought through tears to affirm our decision

and to tell me her story, that she really wasn't talking to me. She was addressing her daughter, and perhaps more significantly, herself. She was reflecting on a terrible choice she was forced to make so long ago.

I remember her twice saying "I know you feel alone." And that was it, really. We had never felt alone. We had felt many things, but never alone. I came to wonder if she had ever had this conversation with anyone.

Ever.

And, reflecting back, I wonder if, unlike my wife and I who had the benefit of contact with so many parents coping with retinoblastoma, if without social media, would this woman simply lacked the technology to communicate with other parents. I wonder if that very technology doesn't also create a disposition, easily misidentified as narcissism, to share the self. To have the courage to contact a stranger. To have the strength to expose oneself. To dance with one's ghosts.

Because that's what I want, I think, if I can claim to know my new self so well. That's want I want my story to signify: that although I could not necessarily control it, I can help others to help me to become otherwise.

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Notes

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This installation was initially delivered accompanied by a Prezi at the 2010 Computers and Writing Conference. To maximize accessibility, I forewent transforming it into Flash and have instead used standards-compliant (x)html and css. In doing so, I fear I have lost some of the affective movement of the original presentation (unexpected transitions and zooms keyed to particular words and ideas). Such fear was confirmed by my attentive reviewers, and I appreciate their feedback. Ultimately, my disdain for Flash's accessibility issues, concerns over bitrot, and the time restraints of academic publication led me to keep the project in standards compliant (x)html and css. I hope that the chronological progression of

images help relate my experience, both trying and joyous, that I cannot reduced to mere words.

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[1] From an interview with USA Today:

It wasn't easy for Madeleine Robb to send an e-mail to another mom warning that her baby might have a deadly form of eye cancer. But she's glad she did it - and so is the mother of 1-year-old Rowan Santos.

"I didn't want to scare her," Robb told TODAY co-host Meredith Vieira from London on Thursday. "But then I weighed out the options. If something wasn't wrong, then no real harm was done. If something was wrong, I really had no option, so obviously I had to tell her" (Considine, 2008).

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[2] Again, I would suggest that Carr's perspective on intelligence is overly-determined by literacy and print. Thus, he feels comfortable reducing intelligence to the filtration of information between short and long-term memory (see Carr, 2010). His arguments on sensory overload are predicated on this reduction. Other scholars in digital studies in Rhetoric and Composition--I am thinking particularly of Gregory Ulmer--might look at the neurological evidence cited by Carr without lamentation; they might interpret it not as the "loss of intelligence" but rather as the transformation of intelligence that calls less for linear rationality (and memory) and more for a logic of assemblage. In fact, one of the assumptions of Steven Johnson's newest work, *Where Good Ideas Come From*, is that interaction and hyper-activity (my term, not Johnson's) helps stimulate invention, rather than cloud or overwhelm it.

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[3] As so often happens, Madeline's particular courage reminds me of another project I am working on--one examining the relationship between Bruno Latour's interpretation of Callicles in Plato's *Gorgias* dialogue and Levinas's suspicions toward ontology. Latour highlights the emphasis courage before the mass body plays in Callicles' rejection of Socrates's rationalism:

The *superior* people I mean aren't shoemakers or cooks: above all, I'm thinking of a people who've applied their *cleverness* to politics and thought about how to run their community *well*. But cleverness is only part of it; they also have *courage*, which enables them *to see their policies through to the finish without losing their nerve* and giving up (491a-b, qtd. in Latour, 1999, p. 239). (emphasis Latour's)

This is a pre-copy-edited version of the webtext, "How the Internet Saved My Daughter and How Social Media Saved My Family," published in the January 2011 issue of *Kairos: A Journal of Rhetoric, Technology, and Pedagogy*. The online version should be cited. It is available here: http://kairos.technorhetoric.net/15.2/topoi/santos.

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[4] It might be interesting here for me to contrast my own difficulties coping with Rowan's cancer to my parents' experiences. Before I was born my parents lost their first child, Benilda, to infant leukemia (a curable condition were she born today). In some ways, they feel as if their loss contributed to the development of medical science--contributed to saving Rowan's life. So, while they have been very supportive and empathetic to our plight, they also perceive Rowan's survival as a kind of validation of their own daughter's death. Thankfully, my parents' story is not solely one of loss. I am learning to appreciate my story as something other than loss as well.

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[5] In researching my own story, I have come across a number of websites that ridicule Megan and I for not realizing that something was wrong. I find a thread on Williamsboard.com revealing. As one of the interlocutors suggests, Rowan's eye looked perfectly normal except in particular photographs. The face that Megan an I did not attend to these photographs earlier likely supports theories that we only see what we can handle seeing.

But I note the Williamsboard.com thread for another reason. The Internet is a mass landscape. It does not necessarily promote ethical proximity. The people on Williamsboard were not in proximity with us (so they thought), and such distance encourages humor. Sure, its insensitive, but funny too (who doesn't like laser beams shooting out of a squirrel's eyes?).

Social media, however, as I am attempting to use the term, speaks to localized groups engaged in particular ethical practices encouraged and facilitated by dialogic technologies.

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[6] Here I would address the potential irony of critiquing literate-print dependencies on narratives in what amounts to be, despite its hypertextual mediation, a linear narrative. What I hope saves me from complete hyporcrisy is the tenor of my narrative; it is not meant to be certain of itself and foreclose questioning; but rather through the tentative and conditional nature of its speculations, welcoming of other responses, angles, and stories. Please send those stories to marcsantos at usf dot edu, or share them on my blog at http://insignificantwrangler.blogspot.com/2011/1/rowans-story.html

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