



**THE MEDICAL  
HUMANITIES  
JOURNAL** OF BOSTON  
COLLEGE  
VOLUME 2 • ISSUE 2



### MISSION STATEMENT

*The Medical Humanities Journal of Boston College* seeks to:

- Initiate and engage in conversation in the Boston College community and beyond about the emergent field of Medical Humanities, Health and Culture.
- Provide students at Boston College with the opportunity to publish original work.
- Feature a variety of work from several disciplines.
- Examine critically and represent creatively ideas of health, illness, caregiving, and medicine.
- Connect students with alumni, professionals, and other Medical Humanities programs to extend and to engage in conversation beyond Boston College.

## **EDITORIAL STAFF**

### **EDITOR-IN-CHIEF**

Russell Simons

### **MANAGING EDITOR**

Theresa Rager

### **DEPUTY EDITOR**

Farwa Haideri

### **LAYOUT EDITOR**

Erin Annunziato

### **PUBLICITY EDITORS**

Amanda Clemente

Megan Fickes

### **WEBSITE EDITOR**

Derek Xu

### **TREASURER**

Mihret Zemedkun

### **EDITORS**

Francine Almeda

Tara Cotumaccio

Katherine Hohne

Kieran Palumbo

Alexander Prete

Emily Sokol

Sarah Ramsey

Liam Townley

### **ADVISORS**

Amy Boesky, *Department Chair, Professor of English and Director of the Medical Humanities, Health, and Culture Minor*

Colleen Taylor, *Ph.D. Candidate in the Department of English and Assistant to the Medical Humanities, Health, and Culture Minor*

### **COVER**

“Statis”

Johanna Tomsick

### **LOGO**

Johanna Tomsick

### **THANKS**

Funding for this publication is provided by the Institute for Liberal Arts at Boston College

Mary Crane, *Thomas F. Rattigan Professor of English and Director of the Institute for Liberal Arts*

Yasmin Nuñez, *Manager of Finance and Administration for the Center for Centers*

Susan Dunn, *Fiscal and Operations Administrator for the Center for Centers*

Ana Tejada, *Fiscal and Events Assistant for the Center for Centers*

The Medical Humanities, Health, and Culture Minor

### **CONTRIBUTIONS**

To read the journal online or find out more information, please visit us at [www.mhjbc.org](http://www.mhjbc.org). Please direct questions or submissions to [bc.mhj.1@gmail.com](mailto:bc.mhj.1@gmail.com).

## **EDITORS' NOTE**

Over the course of our four years as college students, mental health has been a defining topic of conversation. From all corners of the university, students are exposed to a growing dialogue concerning wellness, mental illness, and health resources. On the national level, news sources and studies are continuously revealing the extent to which mental illness is affecting American students, from the secondary to university levels.

These conversations are not just being vocalized; they are being committed to paper. During this semester’s submission cycle, our editorial board noticed strong thematic similarities across a number of the pieces that were accepted. In particular, several contributing authors discussed, commented on, or told stories relating to mental health and illness. Whether writing on anxiety, depression, self-image, or eating disorders, this semester’s contributors depict poignant scenes of the daily, and often hidden, struggles of mental illness.

In this edition of *The Medical Humanities Journal of Boston College*, Sherry Hsiao writes both “The Myth of Full Recovery” and “Before I Sleep.” The former uses personal, scientific, and artistic perspectives to examine why people feel compelled to hide because of mental illness, while the latter presents a vivid, tangible, and honest look at a nighttime routine derailed by depression.

Andrew Zeppa’s “An Abusive Relationship with Myself” takes the reader on a journey through a years-long battle with an eating disorder, intertwined with familial trauma, a quest for self-acceptance, and an eventual recognition of what matters most.

“Anxiety” by Sarah Ramsey takes place within a patient’s mind during a routine doctor’s examination, elucidating the racing thoughts and onslaught of emotions that arise from a stressfully-perceived test.

The rise of social media has dual effects on mental health,

both leading to a promotion of mental health resources and a diminution of users’ self esteem. “Faceless” by Sophia Ihlefeld describes this juxtaposition, detailing cyberbullying as a cause of mental illness and health blogs as outlets for support and information. Ultimately, the increased ability to compare oneself with others can prove detrimental to our emotional psyches.

Although we were aware of the growing number of voices joining the mental health conversation on our campus and across the nation, we were surprised to observe such strong thematic connections across pieces in this edition of the journal. Similarly Dr. Susan Reverby was aware of the ethical violations of the Tuskegee Syphilis Experiments when she entered the archives but was surprised to stumble upon a grotesque violation of ethics in Guatemala. In “A Historian Walks into an Archive,” Reverby reminds us that we may not always find that which we are looking for, but that in our process of discovery we can unearth new information and insights. In calling attention to these historical discoveries, she tells of bioethical concerns our society has selectively hidden.

As always, we are honored and grateful that these authors have shared their work with us, particularly when doing so means sharing deeply personal life events. We would like to especially thank our editorial board, advisors, and readers as we continue to explore the medical humanities in all their richness and power.

With enduring gratitude,

**Russell Simons and Theresa Rager**

EDITOR-IN-CHIEF AND MANAGING EDITOR

The information provided by our contributors is not independently verified by *The Medical Humanities Journal of Boston College*. The materials presented represent the personal opinions of the individual authors and do not necessarily represent the views of *The Medical Humanities Journal of Boston College* or the Boston College community.

*The Medical Humanities Journal of Boston College*, Volume 2, Issue 2, Fall 2016  
Mailing Address: 10 Stone Avenue, Chestnut Hill, MA 02467  
Copyright © 2016 by the Trustees of Boston College

GUEST  
CONTRIBUTOR

SUSAN M. REVERBY, PhD

PAGE 41

RESEARCH

Courts and Controlled Chaos: 14  
An Interpretation of Medical Decision Making for Incompetent Patients Through Art  
*Elizabeth Magill*

Ethical Dilemmas to Ambiguous Definition of Autonomy: 31  
Advanced Care Planning and End of Life Decisions for Cancer Patients  
*Elizabeth Magill*

Faceless 56  
*Sophia Ihlefeld*

Turning Inward 20  
*Johanna Tomsick*

Sketchbook 55  
*Johanna Tomsick*

ART

NARRATIVE

An Abusive Relationship with Myself 6  
*Andrew Zeppa*

The Anatomy of Todd Melkin 21  
*Cat Malcynsky*

Paper Boats, Painted Stones, and 44  
Parkinson's  
*Megal Lee*

Mental Illness: 48  
The Myth of Full Recovery  
*Sherry Hsiao*

Before I Sleep 66  
*Sherry Hsiao*

POETRY

The Clinic 9  
*Katerina Ivanov*

I Wear Glasses on My Ears 10  
*Sarah Ramsey*

I Have a Bug in My Ear 12  
*Sarah Ramsey*

Anxiety 46  
*Sarah Ramsey*

---

# A N ABUSIVE RELATIONSHIP WITH MYSELF

ANDREW ZEPPA

*“From the outside looking in, you can’t understand it. From the inside looking out, you can’t explain it” (Anonymous).*

Ravenous, insatiable hunger. A hunger for relief, numbness, and escape—a high. My mind is spinning. Spinning and spinning around a warped mirror that reflects a physical reality awash with shame and judgment: spinning so fast that it fails to comprehend or even sense that which is distinct from the tangible.

The depression, the anxiety, the rage, the guilt, the lust, all exist as visceral sensations occupying a locus not on my mind, but on my body. Quench it. With anything and everything and as fast as possible. Fill the void. Cathartically eliminate the squalor. Just another serving of my sordid burden, drenched in self-loathing, a cherry on top.

I am a twenty-one-year-old man, and I have been in an abusive relationship with an eating disorder for the last decade of my life. Ten years of *you’re fat* and *not good enough*, of starving for perfection, of addiction and compulsion. But it wasn’t all one-sided. While I provided him with a body and mind to control, he provided me with a relief mechanism, a method of avoidance, and a measure of self-worth. For ten years, he assuaged my depression and anxiety, but made me feel guilt and shame. Ten years of desperately trying to feel in control, no matter how out of control things might have actually been.

In my Italian family, food is central to the expression of emotions. Celebration, gratitude, and mourning alike are marked by an excess of edible sentiments, passed from hand to hand, plate to plate, in a ritual exchange of affection. Unsurprisingly, it was from an early age that I began to forge associations between food and feelings.

*My dad and I are preparing peanut butter cookies. He shows me how to create crisscross fork marks on the dough before placing them in the oven. The sweet smell of freshly baked love and togetherness permeates my mind.* I can still taste the memory if I concentrate hard enough. Unfortunately it is a memory never to be recreated.

When I was eight years old, my dad died from multiple myeloma, a cancer of the bone marrow. His funeral was on a warm June day, the sun shining behind just a few innocent wispy clouds. I remember playing on the church playground with my cousins that afternoon during the reception. Children are remarkably resilient. But lurking within the carefree, seemingly unfazed child was a scared and emotionally stunted spirit.

As only death can do with such potency, the tragedy brought together my extended family, and my mom, brother, and I

---

spent the summer in the cradle of our kin’s warmth and support. My family’s connections tightened in the following years, a blessing to my and my brother’s childhoods. Likewise, our Catholic faith flowed between us more strongly than ever. Catholicism meant that my dad was in heaven. It also meant that I was fundamentally incompatible with the system in which I was living.

Puberty came in junior high, as did the comparisons that followed. *Why are you so tall and big? You are different. Different is bad. You are bad.* My belief (and the fact) that I was overweight meant that I could protect myself from the emotions and sensations associated with intimacy. If I’m fat, nobody will question my lack of romantic relationships. In my traditional Catholic family, it was imperative that nobody ever found out I was gay. Being close to someone and being real with myself were terrifying to me, so I entered into a relationship, abusive as it was, with my saving grace: the eating disorder. I protected myself with a very physical barrier of excess weight. I became comfortable in isolation, eating away my emotions. Food filled me up, made me whole, and left me fat and unattractive. But it was the protection that I sought.

Things took a turn in high school when, realizing that I no longer enjoyed being alone and isolated, I decided to lose weight. This was a victory for the eating disorder. He had complete control over our intertwined life: *No breakfast. No lunch. Too fat. Unworthy. No breakfast. No lunch. Pathetic. Loser. No. No. No.* But day after day, 4:00 would roll around. School was out, choir practice over, and I hadn’t eaten anything all day. As if the biology of it wasn’t enough, the psychological distress wafting over my adolescent mind created a monstrous force of hunger. A hunger not only for food, but for relief, numbness, and escape. *Binge. Eat until you’re so full you feel like you may burst. Fill the void. Numb out. Be outrageous and bad. Slowly kill yourself, you disgusting, worthless monster.*

Restrict. Binge. Purge. Rinse and repeat.

The cycle was vicious and seemingly unstoppable. Like any addiction, it quickly became much more compulsive than reactionary (something done merely to deal with emotions). I needed him. Thrived on him. When my mom noticed that my behaviors were quite out of the ordinary, she sent me to therapy. But I wasn’t ready to break up with my eating disorder. *You don’t have a mental health disorder. You just lack self-control and willpower. You’re weak and gluttonous and you just need to stop eating so much.* Everything in my life began to revolve around the idea of being thin. Every one of my problems could be traced back to my weight.

Then I realized that food was not the problem. It was merely a symptom. The real problem was that I never grieved. Never grieved the loss of my dad to cancer. Never grieved the loss of a life planned out for me in which I married a Catholic woman and had three children. Never shook the feeling that I am fundamentally wrong and shameful for being gay, that it’s my fault and I’m going to hell for it. Never grieved for all the pain, suffering, and trauma of life. Instead, I ate. And starved. And ate again. Geneen Roth says it best:

---

Compulsive eating is a symbolic reenactment of the way in which we distorted our feelings when we began eating compulsively: we swallowed our feelings; we blamed ourselves; we felt out of control; we believed we couldn't get enough. If we allow ourselves to get sidetracked into believing that food is our problem, we will never heal the wounds that we became compulsive to express.<sup>1</sup>

Eating disorders are not about losing weight. They are not about vanity.

In November of 2015, I decided, with the support of friends and family, to take a medical leave from my studies at Boston College. Home in California, I was admitted to a forty-hour-per-week partial hospitalization program at a comprehensive eating disorder recovery center. In this program, I was afforded the opportunity to empathize with a wide range of other clients' experiences with eating disorders.

The cast of characters was diverse and dynamic. There were recent college graduates—an accountant, a wildlife ecologist, and a social science researcher. A student on leave from Boston University; a fifty-something biochemistry PhD and chief science officer of a biotech firm. A man. A child. LGBTQ and straight. Varying socioeconomic backgrounds, beliefs, and cultures. So what is the common thread between eating disorder patients? I believe that it is, broadly speaking, trauma—whether developmental or acute. In group therapy, we bonded over shared experiences of trauma and loss. From sexual assault to suicide in the family, from bipolar parents to trans-generational shame, we all struggled chronically to deal with overwhelming emotions during which time the eating disorders took over.

Hence the abusive relationship. The disorder offers many things in a time of need, but ultimately proves disastrous when it lingers long after its purpose has been served. Like with all addictions, the cycle drones on, and breaking up the abusive relationship is a time for grieving in and of itself. I've spent half my life with my eating disorder, and it's not easy to let go. But I am blessed with loving friends and family. It is that love—that intimacy—that allows me to break free and strive down my journey of recovery. I am a twenty-one-year-old man, and I am *recovering* from an eating disorder.

There are many things I've learned from my experiences, but chief among them is this: Love is the answer. Only intimacy that stems from authenticity and the present moment can bloom into this kind of love. Whether recovering from an eating disorder or dealing with death and trauma, knowing that someone truly understands the real you and loves you all the same not in spite of your experiences (your "faults"), but because of them—is what allows you to go on. This essay is a stride in that direction. I am here as I am.

**ENDNOTE**

1. Geneen Roth, *When Food is Love: Exploring the Relationship between Eating and Intimacy* (New York, N.Y.: Plume, 1992), 125.

---

# THE CLINIC

KATERINA IVANOV

we're hanging off your bed. you—longer lately, hair brushing at the carpet  
me—thick tongued after your mother's wine. you turn—I'm struck by how  
eye contact is the same, upside down. *punch me in the stomach*, you say.

we do that exchange girls do with their eyes—*are you sure?*  
*how far? you weren't safe?*— all at once. you crinkle me into a fist—  
piano fingers, weak wristed, palms cut with thick fault lines.

*please*, you say. we stand and gravity does this thing to your eyes that nighttime  
does to the neighbors lawns. in the aisle of a drugstore you wash it down  
with diet desperation. we aren't quite sure if there's anything

to grieve that day, so we smart like fresh cuts at the sounds  
of The Smiths on the way home, and I dig half moons into my palms  
while I pretend you are only hiccupping from the soda.

when you do it for real, I stay tightlipped and unlicensed and you don't  
cry in the front seat like you did in ninth grade and I run my fingers through  
my eyelashes like heart strings, mourning the things we should have mourned, then.

---

# I WEAR GLASSES ON MY EARS

SARAH RAMSEY

I know it is not a traditional piece of hardware,  
To wear around the ears,  
But you see,  
I have difficulty seeing sound.

The waves look fuzzy to me,  
Versus the clear jagged lines,  
That construct visible mountains, canyons, and valleys,  
To people that can see sound clearly.

The glasses nestle right in the curvature of my ear,  
And are hardly visible,  
To the naked eye.

Sometimes,  
They reflect sunlight,  
That bounces off the lens,  
And creates a glimmer,  
Attracting the attention of onlookers.

If it happens when I am with someone,  
I can see their brain clicking,  
Trying to register why the inside of my ear is shining.

Why is she wearing glasses on her ears? They ask themselves.  
Has she always had those? I don't remember seeing them before.  
I wonder if I should talk to her louder so she can see better?

It amuses me really.

---

How awkward the onlooker can become,  
When they are faced with the that fact I can't see sound well.

They are so desperate to act politically, ethically, morally, and socially correct.  
They keep jabbering and blabbering,  
As if they didn't notice,  
As if their eyes are not resting on my glasses,  
Nervously darting from one ear to the other.

I didn't say I was blind goddamit!

I just said I can't see sound that well.  
I can still see your judgment, facial expressions, brain clicking, pity, confusion, and fear.  
I am not stupid.

But,  
I am used to this.  
I pretend not to notice the tension that has just formed between us,  
And keep smiling, laughing, and joking like I always do.

I don't mind my glasses,  
I rather like them.

Without this stylish accessory,  
I would be walking around,  
In a murmur,  
That feels like the fuzz on the outside of the peach.

I would be disconnected,  
In my own world,  
Without ears that sparkle like diamonds.

I know it is not a traditional piece of hardware,  
But I wear glasses on my ears.

---

# I HAVE A BUG IN MY EAR

SARAH RAMSEY

Filling up,  
Buzz,  
Hum,  
Ache.

Walls block me in and out,  
They serve as barriers,  
In between confusion and understanding.

I stop what I am doing,  
And walk over,  
What did you say?  
I'm constantly pausing life,  
To answer other people's questions.  
Because what they said is more important than what I didn't hear.

I'm sorry. I didn't catch that.  
I'm sorry. That was my fault.  
I'm sorry. I was spacing out.  
I'm sorry. I'm sorry. I'm sorry that my body is betraying me.  
I'm sorry that I am detached, lonely, and deaf.

Please don't laugh when I looked confused.  
Please don't be confused when I agree to something that wasn't a question.  
Please don't talk to me, please don't listen, please let me be alone.

---

Filling up,  
Buzz,  
Hum,  
Ache.

Murmurs block me in and out.  
They serve as barriers,  
In between confusion and understanding.

I'm tired of being alone.  
I'm tired of being sorry.  
I'm tired of filling up, and only hearing buzz, hum, ache.



---

# COURTS AND CONTROLLED CHAOS:

## AN INTERPRETATION OF MEDICAL DECISION MAKING FOR INCOMPETENT PATIENTS THROUGH ART

ELIZABETH MAGILL

If a competent patient seeks health care treatment, the court has established strict standards that protect the patient's right to determine his or her own care. Stemming from John Stuart Mill's famous declaration "Over himself, over his own body and mind, the individual is sovereign," competent patients have the legal right to accept and deny even life-saving treatment.<sup>1</sup> Since this rise of autonomy between 1960-1990 has been upheld in courts, the decision-making process in cases with competent patients is linear—albeit family members or physicians may disagree with the decision—and ensures that patients' wishes are respected.

In many other cases, however, individuals are incompetent to make decisions for themselves, which begs the question: Who decides? There are many categories of incompetent patients in medical cases, including children, mentally ill, unconscious, and profoundly mentally compromised. Family members and physicians compete for power in such decisions to attempt to prove that they know the best interest of the patient. As explained in *Responsibility for Decisions*, "the image of isolated patient interacting with isolated physician is a myth."<sup>2</sup> Instead, decision making revolves around perspectives of patients, physicians, family members, and even the hospital, professional boards, insurance and society. This chapter continues with an example of the question of continuing care for a dying newborn infant with trisomy-18. The father did not want to save the child unless it could be "normal," which created questions about

the concept of normalcy and the mental state of the father, while the nurse in charge of the baby believed that the life should be saved at all costs; meanwhile, the chief of pediatrics and social worker have their own opinions about others' decisions. The chapter argues that one perspective cannot tell the entire story, but viewpoints must interact to illustrate facts and ethical values at stake.<sup>3</sup> With such diverging opinions, however, how can the best interest of the patient be recognized?

It was in reflecting on these often antagonistic and multifaceted perspectives that I entered the Museum of Fine Arts Boston to explore art through the lens of medical decision making and quickly noticed *Splendid* by Shinique Smith, a modern piece that consists of a large opaque turquoise wood panel with a large mess of tangled webs of intersecting paints and strings. Each layer of acrylic paint, ink shapes, and braided yarn overlaps to create texture in this work, some combining together yet each noticeably distinct. Most protruded from the wood are eight pieces of scrunched fabric randomly assorted throughout the piece, attempting to conjoin into some sort of harmony or clarity. I resonated with *Splendid* because of its concise connection to health care decision-making—the confusion and tension of these decisions mirrored in the piece's overwhelming colors and medium. With so many pieces of scrunched fabric, there is no focal center to the piece, no consensus of the correct interpretation or health care decision. Just as

patients' wishes are somewhere within others' perspectives, the first layer of the work remains intact, yet it is hidden by other diverging subsequent layers and can never be fully retrieved. My interpretation of abstract art reveals my own identity in relation to the work in the same way that perspectives of the best interest for patients are skewed by relationships and identities of each individual in the discussion. In the end, all we see is a tangled mess.

One landmark case that represents the complexity of medical decision-making for the incompetent is the case of Karen Ann Quinlan, a twenty-one-year-old woman who went into a comatose state after drinking alcohol and ingesting Valium at a party and ended up in a persistent vegetative state. After three and a half months of no recovery, the Quinlan family decided that "Karen would never want to be kept alive on machines like this" and signed a letter authorizing their discontinuance of a ventilator.<sup>4</sup> Despite initial approval, Dr. Morse told them the next morning that he morally refused to follow the family's request, which plunged the Quinlan family into a battle to gain approval to remove the ventilator and allow Karen Ann to die.

The Quinlan case, in addition to being a case of first impression, contained moral and religious elements that complicated decision-making. Catholic groups protested the Quinlan family's distinction between ordinary and extraordinary means to sustain life, despite their bishop's approval.<sup>5</sup> The case also evaluated the distinction between killing a patient and letting a patient die that was later reestablished by the 1980 Vatican Declaration on Euthanasia: "One cannot impose on anyone the obligation to have recourse to a technique which is already in use but which carries a risk or is burdensome. Such a refusal is not the equivalent of suicide; on the contrary, it should be consid-

ered as an acceptance of the human condition."<sup>6</sup> Confusion about opinions, moral standards, and the best-interest of Quinlan led to an intense dispute before the final decision to allow removal of the ventilator.

While comparing health care decisions for the incompetent such as Quinlan to *Splendid*, it is easy to espouse an only negative view of the complexity of health care decisions—these intricacies create tension and extend the decision-making process. As I continued through the Museum of Fine Arts, however, I kept returning to an impressionist piece entitled *Rehearsal of the Padeloup Orchestra at the Cirque d'Hiver*. In this painting, an orchestra rehearsal is illustrated sectioned into instruments; cellos, violins, trumpets, and a large drum sit separated in the amphitheater. At first glance, *Rehearsal of the Padeloup Orchestra at the Cirque d'Hiver* echoes *Splendid*'s twirling chaos with noticeably impressionist, large, swirling brushstrokes from the upper left-hand corner of the piece, but the painting remains centered by a conductor on the left hand edge of the frame. All sections face the conductor, playing their instruments in the midst of an arrangement.

The idea of an orchestra, blending sounds from different instruments to create beautiful musical compositions, in its rehearsal phase captured for me the power of controlled chaos. Each instrument adds chords and progressions to the piece—impossible without their combination; and with guidance from a conductor, the sections remain balanced for full effect. The conductor holds the most important role of an orchestra, keeping time and bringing in all different parts to ensure harmony; with that role, it is only fitting that the brush strokes forming the orchestra revolve around the conductor in *Rehearsal of the Padeloup Orchestra at the Cirque d'Hiver*.

---

To attempt to create clarity out of confusion and move from images of *Splendid to Rehearsal of the Pasdeloup Orchestra at the Cirque d'Hiver*, the American health care system has turned to the courts as adjudicators for medical decision-making; judges sit as conductors of the orchestra of health care. For cases where patients are incompetent, the court has established that patients still have the legal right to autonomy in decision-making, although their autonomy might be more difficult to ascertain: "the recognition of [a general right in all persons to refuse medical treatment in appropriate circumstances] must extend to the case of the incompetent, as well as a competent patient because of the value of human dignity extends to both."<sup>7</sup> The role of the court, then, has become to follow the English doctrine *Ex parte Whitebread* and "don the mental mantle of the incompetent" to help identify the best interest of the patients in these cases.<sup>8</sup>

Legal cases of first impression such as *Quinlan* establish standards that limit the necessity for other prolonged legal battles in similar cases. The *Quinlan* case created the 'reasonable person' standard to identify what an incompetent patient would want, a "principle that allows a surrogate decision-maker to attempt to establish, with as much accuracy as possible, what decision an incompetent patient would make if he or she were competent to do so."<sup>9</sup> Another case of incompetency, *Mr. Saikewicz*, a sixty-seven-year-old man who was profoundly mentally retarded and needed treatment for leukemia, set a standard of substituted judgment for a court to "substitut[e] itself nearly as possible for the incompetent, and acting on the same motives and considerations as would have moved him."<sup>10</sup> These standards act as precedent for other legal cases regarding the treatment of incompetent patients, allowing for clear consensus amidst overlapping acrylic paint and ink perspectives.

Despite courts' concise conclusions about medical cases, many question whether courts are the appropriate conductor for medical decision-making. When asked whether she believed that her husband's case to remove a gastrostomy tube was best handled in the legal system, Mrs. Brophy, the wife of a firefighter who persisted in a vegetative state for three and a half years, stated that she thought the courts were the worst place to make medical treatment decisions due to the pain and suffering of the family during that elongated legal process, which for her took years.<sup>11</sup> Mrs. Brophy's sentiments have been echoed by physicians, family members, and even judges alike in different situations. As Judge Warren Burger stated in his dissent in *Georgetown v. Jones*, a case about request for a blood transfusion for a Jehovah's Witness, "There are myriads of problems and troubles which judges are powerless to solve; and this is as it should be. Some matters of essentially private concern and others of enormous public concern, are beyond the reach of judges."<sup>12</sup> Because of the grave importance of medical decisions, lack of medical knowledge of judges, and minimal state interest in private decisions, some consider medical cases, particularly cases where the patient's wishes cannot be clearly ascertained through competency, instances in which the law has no place.

In some cases, judges have created controversy in medical decisions for the incompetent by relying on their beliefs rather than medical information, such as in the probate court decision of the *Saikewicz* case when Judge Jekamonski ruled based on what his own wishes would be in the situation: "I feel that if I had a serious disease and with treatment I could live another five or eight years or ten years, whatever I'd rather take the treatment than just take the chance of dying tomorrow or next week."<sup>13</sup> By ruling based on opinion without consideration of *Saikewicz's*

profoundly mentally-incompetent state or the medical facts arguing that *Saikewicz* will never see his treatment competently, judges such as Jekamonski step outside of their assigned role, which is clearly not in the best medical interest of the patient.

More importantly, the use of the legal system to resolve medical disputes conflates the law with morality and pits physicians and families against each other instead of promoting a collaborative relationship for the benefit of the patient. Richard McCormick argues that the law and legal entities are one of the five main factors pushing bioethics into oblivion. He, quoting Gilbert Meilander, states that "if...we understand the point of law to be chiefly the empowerment of self-defining private choice, and if moral discussion has been folded into discussion of what the law should be, we have effectively eliminated from public consideration a wide range of moral concerns."<sup>14</sup> By limiting discussion to the legal framework of decisions, ethical issues such as human dignity are ignored, and standards reject these moral influences. At the same time, since the legal system requires two sides for debate and allows for continual appeal of cases, the legal authority of courts has isolated physicians and families from discussing non-legal ethics or even collaborating on general medical treatment. Legal involvement in health care disputes has only strained an already broken physician-patient relationship, or in this case physician-family relationship. While Jonsen argues that the best outcome for the patient requires such teamwork: "Doctor and patient, each with their own needs, desires, capabilities, must find those principles that allow them to coalesce into a helping, healing alliance to achieve a common goal."<sup>15</sup>

While the American health care system has chosen the

court system as a conductor to help harness decision-making for the incompetent from controlled chaos, the correct role of an arbitrary legal entity in moral and ethical decision-making remains unclear. Standards set by the courts have established legal guidelines for subsequent cases, such as in *Quinlan* and *Saikewicz*. But if these cases are inherently ethical, do judges have the authority to make moral decisions?

No matter the answer to this question, the court remains the current final authority in American health care, although ethics committees, established in the *Quinlan* case, are beginning to oversee increasing numbers of cases in hospital settings.<sup>16</sup> One conductor, albeit a potentially poor conductor, places medical decision-making for the incompetent somewhere between *Splendid's* chaotic web and *Rehearsal of the Pasdeloup Orchestra at the Cirque d'Hiver's* rotating symphony. Luckily, however, it is only rehearsal.



*Splendid*  
Sinique Smith, 2014



*Rehearsal of the Parsdeloup Orchestra at the Cirque d'Hiver*  
John Singer Sargent, 1879-80

#### ENDNOTES

1. J. Stuart Mill, "On Liberty," (1869).
2. "Responsibility for the Decision."
3. Ibid.
4. R. Munson, "Karen Quinlan: The Debate Begins," in 5. *Intervention and Reflection: Basic Issues in Bioethics* (Boston: Wadsworth, Cengage Learning; 2012): 190-192.
5. A.R. Jonsen, R.M. Veatch, L. Walters, "Reexamining the Role of Traditional Moral Distinctions," in *Source Book in Bioethics: A Documentary History* (Washington: Georgetown University Press, 1998): 169-178.
6. The Sacred Congregation for the Doctrine of the Faith, "Declaration on Euthanasia," (Vatican City: 1980).
7. *Superintendent of Belchertown v. Saikewicz* (Supreme Judicial Court) (1977).
8. Ibid.
9. "Doctrine of Substituted Judgment Law"
10. *Superintendent of Belchertown v. Saikewicz* (Supreme Judicial Court) (1977).
11. In Class Lecture, Questions with Mrs. Brophy (04/05/2016)
12. *Application of President and Directors of Georgetown College*, 331 F. 2d 1000 (D.C. Cir. 1964).
13. *Belchertown v. Saikewicz*, 370 N.E. 2d 417 (Probate Court) (1976).
14. R. McCormick, "Bioethics: A Moral Vacuum?" *America* (May 1, 1999)
15. A. Jonsen, "Medical Ethics and Research Ethics: The Role of 'Autonomy' Revisited." (November 14-15, 2008): 1-5.
16. R. Munson, "Karen Quinlan: The Debate Begins," in *Intervention and Reflection: Basic Issues in Bioethics* (Boston: Wadsworth, Cengage Learning; 2012): 190-192.



---

# THE ANATOMY OF TODD MELKIN

CAT MALCYNKY

After seeing an episode of *Law & Order* in which a mother murdered her infant child by forcing it to swallow a kitchen sponge, forty-one-year-old Todd Melkin was even more convinced that he had a tumor in his brain. The television morticians found crystallized dish soap between the baby's brain and skull, and Todd decided that's what it felt like – like misplaced disinfectant, chemical and ravenous.

Todd had first decided on the tumor's existence when he was sixteen. He could feel it even then, sinking its roots into the folds of his frontal lobe, pushing angrily against his skull. Come December of his sophomore year of high school he was quite sure of it, but not certain enough to tiptoe into his parents' bedroom and whimper the words to his mother. He didn't know if he wanted the doctors inside of him, asking him to recite the colors of the rainbow while they poked and prodded. He thought of the starched white coats and the smell of latex and the fluorescent glare off linoleum floors. He worried that the tumor was smarter than they were.

He thought maybe he could wilt it like a flower, and for over a day he didn't drink anything. But the internal drought proved to be too difficult; he could feel its dry, chalky residue pollinating his cranium. So he tried to drown it, drinking so much water that it felt like his stomach might give way, until his throat was swollen in protest. The pain passed and Todd felt the tumor finding its footing again, having simply floated from one side of his head to the other.

For years it slept, Todd reasoned, swaddling itself in his grey matter and tucking itself in between layers of Todd's subconscious. He feared angering it by means of articulation, so he ignored the beating of its separate pulse until it slowed into slumber. Todd grew up a lot and down a little; he grew older and more tired and even grew a rather brittle goatee. From seventeen to forty-one the tumor hibernated, awakened not by sound but by silence.

*...Side effects include nausea, dizziness, loss of appetite, loss of interest, sleep loss, and in severe cases...*

Forty-one-year-old Todd turned off the television. It zapped to black. He missed the way their old television turned off – the pixelated colors shrank away from the corners into a single white dot that flickered out. He preferred things that ended gradually.

...

## TURNING INWARD

Johanna Tomsick

---

“I have a headache,” Todd said into the phone. The opposing voice of his mother cooed sympathetically before casually letting slip that she, too, had felt ill that morning. That kind of thing drove Todd crazy. Why couldn’t he be the only person with a headache for once? Why was it that whenever he told someone he felt weary, they felt the need to share some saga about the horrific flu they had last week? He sat, brooding in the corner of the coffee shop, until his mother finally let him go. He grunted a goodbye into the receiver, followed by a muttered “stop worrying about me.”

Then to the computer screen. Numbers and letters and columns and such. Finances for a hot tub manufacturing company (Rub-A-Dub Hot Tubs!). He turned the brightness of his screen down low; he wasn’t lying about the pounding behind his temples. Eight months ago he would have handled this at home, fiddling with fonts and margin alignments for a good twenty minutes before actually getting to work on anything substantially worth his time. But he was better now. More driven, focused. At least he wanted to be.

“Hey, Todd.”

Todd glanced up only briefly at the sound of Dawn’s voice. “Hello.”

“Just water today, I assume?”

“Yes, thanks.”

She was a sweet woman. Impossibly old, but sweet. She always smiled at him appreciatively before he even reached the barista counter, probably because she knew he wasn’t going to ask for anything fancy. Nowadays everyone who came in here spoke a second language, rolling “-accinos” and “-acciatos” off their tongues rapid-fire, tying together English and Italian with styrofoam and different medleys of espresso. It boggled Todd. He didn’t even like coffee, and the thought of lying awake for hours in bed, writhing with caffeine, certainly wasn’t worth the price. Water was free, a constitutional right.

He would ditch the groaning grinders, hissing steamers and constant babble of the coffee shop if he could still get anything done at home. There was no noise in his apartment to clutter his thoughts, since his radio was broken and the second dresser in the bedroom had been cleaned out. Home was for sleeping and eating breakfast, because breakfast food was easy to buy and takes longer to expire. So he came here after work, plowed through his nightly workload, and then found some dimly-lit place with a booth and a vodka tonic and ate until he was tired enough to actually sleep.

Five months ago he didn’t live like this. Five months ago he had still been bald (“doesn’t your head ever get sunburned?”) with that goatee (“babe, this thing has gotta go”), but he had also been about twenty pounds lighter, without the swell of a beer belly threatening the last hole of his belt. He’d had that glow about him that let strangers know that he wasn’t lonely

---

in life, and he had rushed home everyday at four o’clock without hesitation or a headache. Back then it was at his kitchen table that he sat and fiddled absently between Calibri and Arial Black, listening to Caroline hum Eagles songs as she started brewing a fresh pot of coffee. He didn’t drink coffee then, either, but he’d always liked the smell.

...

“They caught it early” – that’s what he imagined they’d have said if they drilled into the tectonic plates of his skeleton and were welcomed by his tumor in full-bloom. Early because it would be five in the morning, when bad news usually comes. Early because he was relatively young, and youth was supposed to ward off ill fortune. They’d catch it early but it would still be too late.

Forty-one-year-old Todd lay in bed, running his fingertips over the sandpaper skin of his head (he needed to shave soon). The ceiling fan churned the cool air of his bedroom, the thin metal chain that dangled from its center swinging in small circles. He’d drawn the shades, but threads of the orange streetlight still slipped through the slats, projecting onto the walls in neat parallel lines. It was quiet but not silent, and this difference is what kept Todd awake. He didn’t mind the subtle whooshing of the ceiling fan – it was the creaking that he didn’t like. Like a child bouncing on a wooden diving board, too excited to back off, but too frightened to jump in. It was loudest just below the skin, pressing back against his fingertips.

*If it were a tumor, you wouldn’t have felt it like that*, Caroline had said one night at thirty-three, when the two of them were swaddled in sleeping bags up in Maine. *There aren’t nerves like that in your brain. It must have been a mental thing – Major depressive disorder, or something.* Todd had laughed as Caroline’s fingers swirled across his chest, her cheek pressed against his shoulder. *Major Depression, reporting for duty*, he’d said, bringing a hand to his forehead in salute. It was funny then because he didn’t feel it anymore.

...

Dr. Zaul had long, brittle grey nose-hairs, and Todd considered them inappropriate for a dentist. For every hour Todd was sentenced to the examination chair, Dr. Zaul was either unaware or unashamed as he stared down the bridge of his infested nose into Todd’s mouth. The hairs reminded Todd of sea urchins, creeping out of Dr. Zaul’s nostrils and quivering with his nasally voice. On occasion a droplet of mucus would cling perilously to a follicle or two, and Todd would watch it with unyielding eyes, fully prepared to tuck and roll out of his chair should that droplet detach itself. Todd often fantasized about trimming the hairs, first with tiny cosmetic shears and then with a top-shelf electric nose-hair trimmer, the kind that sounds a lot like the contraption that Dr. Zaul was forcing between his molars. Todd mused that he might even tuck the necessary tools into the pocket of his blazer, and subtly begin the nasal deforestation while Dr. Zaul was simultaneously beginning the dental cleaning. It could be a beautiful symbiotic relationship, like shark and a remora, or a hippo and one of those tiny birds that eats bacteria off a hippo’s back. Dr. Zaul might not even notice.

---

“Well, aside from the one cavity the ol’ chompers are holding up well, Mr. Melkin.” Todd winced at the word *chompers*. “I’m glad to see you here, I hear it’s been a tough year for you.” Todd nodded, hoping his gaping mouth did not undermine the somber tone of his nod. “A little wider, please,” Dr. Zaul said politely. His nose-hairs danced. Todd dropped his chin, feeling like his chapped lips might split. He never knew what to do with his tongue; it was embarrassing not to know its orientation.

“Did you and Caroline sort it all out?”

“*Nuhh-uh.*”

“Well, that’s just too bad.”

“*Uhh-huh.*”

“She was a sweet lady.”

“*Uhh.*”

Dr. Zaul employed a new tool now, the kind that gently spouted water into his mouth. He imagined his tongue, dry and shrunken, expanding like a sponge as it absorbed the needed moisture.

Todd realized he was clenching his hands together so tightly over his stomach that it hurt his fingers. He wrung his hands and tried to place them at his sides. He picked at where the worn leather tucked under the chair’s metal foundations. Dr. Zaul was at the sink now, mixing something together.

“We just need you to make an impression now,” Dr. Zaul went on, scraping a purple-colored clay into what looked like a mouth guard. “Bite down,” Dr. Zaul said. Todd wrenched his jaw open again and sank his teeth into the putty.

...

Todd drove to work without any music, for fear that his tumor might dance. Instead he focused on the sound of the wheel sliding through his hands, the brief roars of the lawn mowers he passed, and the starchy film left on his teeth by the impression. Todd preferred the web of back roads that led to his office, even though David, his closest work acquaintance, insisted that it was a waste of time. Todd counted mailboxes, sometimes adding up the sums of their street numbers. He assigned names to the spaniels and retrievers that pulled at their leashes. When stick-figure murals made of sidewalk chalk waved at him from a driveway, he winced at the pain in his head and tried his best not think about Caroline.

---

He parked in his usual spot, the one closest to the street and farthest from the office, where there was never any anxiety over finding an empty space. The sun was hot as he ambled to the door, and he wished he hadn’t worn such a thick tweed suit.

“There’s the champ!” bellowed David as soon as Todd had stepped into the foyer of Rub-A-Dub Hot Tubs!. He air-punched Todd’s bulging stomach; this almost bothered Todd more than the unconvincing use of “champ.” They had worked together for fifteen years and they still didn’t understand each other.

David began his first irrelevant anecdote of the day by saying “it’s not even funny,” but Todd heard “it’s 1914.” He knew this wasn’t right but he let himself run with it, dubbing over David’s recap of his wife overcooking the pot roast again with thoughts of what the office would look like if it were, in fact, 1904: dustier, he decided. Edith and Megan would be in corsets (and probably churning something back in their respective homes). The electricity would have to go. Or would it? He made a mental note to look up when electricity was invented. Edison was the guy, that much he knew.

“Can you even believe that?” David asked, clapping a hand onto Todd’s shoulder. Todd shook his head, imagining David in pantaloons and a powdered wig. “. . . And with a stomach full of *charcoal stew*, I had to read a children’s book about a rabbit throwing a dinner party about fifteen consecutive times before Archie and Emma would go to sleep. Exhausting, I’ll tell ya! Sometimes I think you made the right call, champ. Not procreating,” David snorted, slapping Todd’s back in an avuncular fashion.

They strode past model after model of state-of-the-art hot tubs, all of which deteriorated Todd’s 1904 fantasy. “Massage jets” and “Dead Sea filters” could not be reconciled with simplicity and tradition. Besides – if it were 1904, David would never think Todd had made the right call; everybody had kids back then, didn’t they? Would Early-Twentieth-Century-Todd have been able to grow into a father? If he and Caroline had met in 1889, would they still be together in 1904? He pictured a long lace-sleeved dress and a feathered sunhat on his bedroom floor.

“I’m sure Kathy didn’t mean to burn your soup,” Todd told David. His voice was hollow.

With every step, the diving board creaked.

...

That night, Todd had a nightmare that he was getting into a hot tub, buck naked, in the middle of the Rub-A-Dub-Hot-Tubs! showroom. Edith and Megan giggled at his pasty thighs, the way his wiry chest hair had become sparse. David heckled the “little champ” between his legs. Marion, his boss, threatened his employment with a shake of his gold-watched fist. Todd sank into the white water, impervious.

---

The heat of the hot tub seeped into his pores. The pressure of the jets pounded the flesh of his back, the soles of his feet. If he were to respond to the crowd of his opposers, he would have sounded like he was shouting into the blades of a fan; he didn't want to say anything.

His flustered audience dissipated, and he was alone. Alone, save for the simmering in his pate. The dregs of the tumor bubbled across his cognizance, coloring the chlorinated water a deep lavender. He could smell them – Caroline's bath salts. "The Muscle Melter – Fun for the Whole Family," read the sign adjacent to the model tub. Todd tried to sink his heavy body under the humming surface of the water, but the tumor kept him afloat like a buoy.

Todd awoke with a start, his head floating off the pillow with nauseating buoyancy. In the cacophony of silence he heard Eagles songs. *Take it easy*, they crooned, but he couldn't. He spread his limbs across the mattress in an effort to shrink the empty space. He remembered being a child, tiptoeing into his parents' bedroom and wriggling in between them to ward off the nightmares. His father was alive then, the cancer having not yet made up its mind. He would die three months before Todd's sixteenth birthday, when Todd was too old to take refuge in their queen-sized sheets.

*I don't want to be a father*, he had told Caroline eight months ago. She was holding onto a cup of Sumatra and a fraying hope that he might change his mind. What he'd wanted to say was "I *can't* be a father," but he knew what would follow – he didn't need encouragement, didn't need reassurance. He knew his makeup, knew he couldn't make enough room in their bed, knew that he carried the gene for cowardice, knew the hibernating growth beneath his brow would one day yawn and stretch its branches. He was never sure when he was going to disappear. In the end, it was Caroline that vanished.

He fumbled with his nightstand and retrieved a sleeping pill. He popped it into his mouth and swallowed it dry.

...

The next day Todd drove to Dr. Zaul's office. Even after he'd parked his car, he kept his hand on the wheel, breathing heavily. His head ached. His ring finger glinted in a shard of sunlight. His fingers had grown too swollen to shimmy the gold band over his knuckles. Too few walks and too many beers.

He didn't have an appointment. He had been to the dentist only a few days before. There was nothing wrong with his filling. Dr. Zaul was not expecting him. Todd slipped his right hand into the pocket of his blazer and ran his fingertips over the electric nose hair trimmer he had stowed there that morning. It was heavy in his pocket, the handle smooth and cold to the touch. His pulse was thick around his temples.

Todd got out of the car and walked briskly into the dentist office. He marched up to the counter and stopped there, staring through Pamela, the mousey secretary. She smiled at him. There was lipstick on her teeth.

---

"Good morning, Mr. Melkin," she chirped. She looked surprised to see him. "Is everything alright? I don't believe you have anything scheduled for today..." she licked her thumb and shuffled through her papers. She should use a computer, Todd thought. It's neater.

"I don't have an appointment," Todd said. His voice came out colder than he meant it, and he felt a bit bad about it. Pamela's penciled-on eyebrows raised, and she paused in her file-fumbling.

"What can I help you with, then? Are you scheduling a future appointment? If so, you can always give us a call." She was looking behind Todd now at a young woman who had just walked in. She seemed eager to dismiss Todd, which annoyed him.

"I need to see Dr. Zaul."

"He has a patient, Mr. Melkin." Pamela's usual sweet-tea tone was icing over.

"I am a patient."

"Not today, I'm afraid. If you could –"

"NO," Todd bellowed, slapping a hand against the desk. Pamela and the woman behind Todd both gasped. "I need to see him *now*."

Pamela was abashed. "I will see if he can spare just a minute of his time," she replied, slowly and firmly.

"Thank you, Pamela." Todd could feel a rush of heat overtaking his face, his palms, his underarms. He abruptly felt tired, so much so that sleep seemed an urgent matter, and even as he saw Pamela bustling back into Dr. Zaul's office he was unsure that he could wait for her return. He leaned against the reception desk; the nose hair trimmer in his pocket clinked against the edge.

"Mr. Melkin?"

Dr. Zaul looked professional as always, crisp shirt and ironed pants, his shoes so shiny that it was almost irritating. He gave Todd a lukewarm smile that politely requested an explanation for this conversation. Todd stared at the edges of his nostrils, where the very tips of the grey anemones barely poked out.

---

“Mr. Melkin, is there a problem I can help you with? I’ve only got a moment, I’m with another patient and her fluoride treatment will be over in sixty seconds. What can I do for you?”

Todd’s fingers enclosed around the trimmer in his pocket. He could feel the ragged breaths invading and fleeing his body. Behind his rectangular, wire-rimmed glasses, Dr. Zaul’s eyes were beginning to look more concerned. Todd’s heart seemed to have stepped onto a treadmill.

“Mr. Melkin?”

Like a hippo and a bird, Todd thought. Dr. Zaul’s breathing quickened as he glanced down at Todd’s hand held tight in his pocket; the nose hairs fluttered.

“Are you alright?”

*You’ll be alright*, Caroline had said. Her hand had been on the door. He had watched her go.

Todd’s hand fell out of his pocket, leaving the trimmer inside. Todd’s eyes fell to the floor and his chest caved, leaving him a slumping mess. “I’m not alright,” he gasped, clawing at his head with his fingers. “I’m *not* alright!” he said again.

Dr. Zaul’s hands gripped his arms tightly, forcing Todd to look up at his bespectacled eyes. “Go home, Todd,” Dr. Zaul whispered, surveying the uncomfortable patients waiting behind them. “You’ve been through a lot lately. If you don’t have anyone to talk to, call Pamela later and maybe she can write you in for one of my lunch breaks – maybe we can get coffee for a few minutes next week, or something, if you think that would help. This isn’t about your teeth, is it?”

Todd heaved in the air necessary to reply. “No,” he said. “It’s not my teeth.”

“Okay,” Dr. Zaul breathed, releasing his grip. “Then that’s the most I can do for you right now. Go home, okay? Take a bubble bath or something. Get some sleep.”

...

Todd did not go to work after that. He went to the park where he proposed to Caroline. He had asked her on a bench that faced the lagoon. They were feeding ducks. In nights before, he had tried to translate Caroline into spreadsheets of pros and cons, risks and benefits – but ultimately his love for her defied his pattern of hesitation. They were happy. He was happy. According to David, “love” and “happy” were words that three-year-olds understood in full, even using them avidly in conversation. At forty-one, Todd had forgotten how they worked; the vowels and consonants were stale on his tongue.

---

Now the lagoon was ailing, pushing discarded beer cans and plastic bags around with its algae and lily pads. Kids ruin everything, he thought.

He ignored calls from David, from Marion. He took his shoes off and walked in the grass, but he felt no younger, no less ill. It was a dewy day and the hem of his trousers got wet. A jolly man was playing a harmonica on a rock across the lagoon, and Todd wondered if he had ever felt this way.

Raw and defeated, Todd walked back to the parking lot. He was still holding his shoes in his hand. He was only a few yards from his car when he saw a small turtle meandering across the pavement up ahead. Every movement it made was awkward; it lifted its clawed feet high, bringing them down with such conviction, yet every step offset its balance. Todd felt a fondness for the creature that momentarily detracted from the pain in his head. The turtle’s struggle was slow and lonely, yet he stumbled on. Todd watched it march its clumsy body toward the park, and he could feel its thirst in his own throat, feel the dryness of its skin in his very bones.

When the truck pulled around the bend of the parking lot, Todd didn’t hesitate for the first time in his life. His body, the opposite of aerodynamic, hurled itself across the asphalt – his skin peeled back against the pavement – his chin cracked. His eyes were closed, but his body saw in tangible color – the tires of the truck thudded over the backs of his knees, and the pain screamed red before the blood even started to gallop out of his veins. He cried out, but he wasn’t sure his lungs made a sound, for the echo of his bones cracking shot through his body at a staggering volume. Time stumbled, and Todd forgot for a moment whether he was eight or eighteen or thirty-six or forty-one. Nothing was relevant but the frenzy of his nerves.

When the kaleidoscope of anguish finally settled just enough, he pried open his eyes and saw his fingertips stretched out before him across the ground. Just beyond them, the turtle was flipped onto its back, waving its legs about in earnest.

“Jesus, God!” a voice exclaimed. Todd heard a car door shut. The sounds were underwater. “Are you okay?!”

“No,” Todd wheezed. His lungs ached in disdain.

“I’m calling an ambulance,” the man panted, and he heard the sounds of the truck’s driver rummaging through his car for his cell phone. Todd closed his eyes again, allowing himself to feel the decimation of his lower body. For a moment his mind confused the throbbing of his arteries with excitement.

“Holy *crap!*” A different voice. “Mister, are you okay?! Mister?!”

Todd squinted one eye open, blinking crimson out of his vision. As his eyes adjusted, he saw a small, chubby hand reach



---

down and flip the turtle back over. Flustered and highly inconvenienced, the turtle scuttled away. Behind it, a small pair of hands and knees pressed against the ground.

“I saw the whole thing – that was *rad!*” A freckled face was brought before Todd’s, the buck-toothed child crouched low. “You *saved* that turtle! You’re a hero, mister!” The boy’s breath smelled like fruit punch. Todd tasted salt. “How do you feel?!” The kid demanded, bringing his face even closer. With great effort, Todd blinked.

“Shouldn’t...you...be...in...school?” he managed.

“You’re bleeding a lot, mister.” The boy’s blue eyes bore into Todd’s, alight with awe and the thrill of fear. “Are you okay?”

“—I-I’m so, so sorry, sir! The ambulance is on its way.” It was the first voice, accompanied by a hot hand on his shoulder blades. “Isaac, leave him alone!” the man added, and Todd watched as the boy retreated in shame.

“No, Isaac...don’t,” Todd mumbled weakly, “not yet.”

• • •

The ambulance was bright light and pricks and tubes he couldn’t feel and agony that muted everything. Isaac’s father told the EMTs that he’d accidentally run Todd over, but didn’t mention the turtle. This bothered Todd. *I wasn’t trying to die*, Todd wanted to say. He wanted to rudely interrupt, like someone with authority. Instead, Todd alternated between opening his eyes and closing them, but both options were starting to look the same.

“We’re almost there, sir,” one of the EMTs assured Todd, and he wondered if they were touching him.

Todd wondered if he should tell them that he had been harboring a brain tumor for the last twenty-five years. He wondered if it would matter. He decided that, if he had just one story left, he would tell them about the turtle. *I was a hero*, he would say. *It was rad*. Besides, he couldn’t feel it just then. What an odd time for a tumor to take a nap, he thought.

---

# E THICAL DILEMMAS TO AMBIGUOUS DEFINITION OF AUTONOMY: ADVANCED CARE PLANNING AND END OF LIFE DECISIONS FOR CANCER PATIENTS

ELIZABETH MAGILL

## Introduction

With an aging population and higher mortality rates in hospitals than ever before,<sup>1</sup> the process of advanced care planning (ACP), or “communication between individuals and their health care agents to...discuss and plan for future health care decisions for a time when individuals are not able to make their own health care decisions,”<sup>2</sup> is becoming increasingly important in the United States. In November 2015, Medicare issued a statement outlining changes that will fund ACP appointments for Medicare patients beginning in January 2016.<sup>3</sup> While this marks a general acceptance for ACP, the process has not yet been successfully utilized for specific illnesses such as advanced cancer. There are a variety of reasons, including younger patient age and unwillingness to appear pessimistic,<sup>4</sup> that doctors are hesitant to discuss death with these patients, but evidence suggests that without ACP cancer patients’ end-of-life wishes are not met. Although most cancer patients want to die at home, unless patients have explicitly discussed or written down their preferences proxies are more likely to provide all care possible than limit life-prolonging treatment.<sup>5</sup> Some of these treatments, including ICU admission, are linked to substantially worse quality of life for patients’ last weeks.<sup>6</sup> Despite the clear necessity for more ACP with cancer patients, the potential for remission makes beginning these conversations extremely difficult.

While it is clear that ACP should be implemented to increase patient autonomy in end-of-life decisions, there is controversy surrounding the timeframe of such interventions; some ethicists believe that ACP should begin as soon as possible, but others argue that these discussions should only be started once cancer is at its terminal stage. Both groups, despite their different perspectives, state that their method best preserves patient choice—highlighting a broader tension about the definition of autonomy in end-of-life medical care.

## Timeline 1: Outpatient Visits after Cancer Diagnosis

Many scholars argue that ACP for cancer patients should occur right after diagnosis of the disease during outpatient oncology visits. This perspective is backed by both the American College of Physicians and Canadian Medical Association<sup>7</sup> and echoes the push for ACP to be integrated into all general adult medical visits. Much of the stigma around ACP, it is argued, comes from the modern stigma around death. Surgeon and public health researcher Atul Gawande, in his book *Being Mortal: Illness, Medicine, and What Matters in the End*,<sup>8</sup> states that with current medical technology, death has become regarded as abnormal rather than part of a natural course, as it was characterized through most of history. He argues that

---

death now comes in stages, with patterns of illness and suffering gradually decreasing quality of life until final death—making it harder to qualify which occurrence will actually signal the end. Because of this, death is uncertain and ACP is ignored. Even with more knowledge about end of life care, the only type of ACP that increased significantly from 2000 until 2012 was durable power of attorney assignment. In 2012, 40% of cancer patients in a study by the *Journal of the American Medical Association* still had not talked about end of life preferences before death with physicians or family members.<sup>9</sup>

In order to reverse this silence, scholars argue that it is necessary to begin talking about end-of-life care as early as possible. Early outpatient oncology visits are seen as the most optimal time to begin ACP primarily because these initial outpatient appointments set standards for future agendas and discussions. Thus, only through initiating ACP directly following cancer diagnosis will ACP be fully integrated into all cancer treatment decisions. This perspective argues that integration is the most important part of ACP, as it normalizes discussions about death and end-of-life early to encourage numerous conversations between physicians, patients, and family members throughout different stages of cancer treatment.<sup>10</sup> While decisions do not need to be made within the first session of ACP, incorporating these considerations into standard cancer care ensures that ACP happens at all. In two studies of cancer patients published by the *Journal of Psycho-Oncology*,<sup>11</sup> 58% and 87% of patients respectively supported a policy in which ACP was offered in the hospital admissions process—45% of the patients in one of these studies did not have advanced directives because their doctors had not approached the subject until they felt emotionally unable to make decisions regarding end-of-life treatment. Interviews with terminal

cancer patients also found that the longer doctors waited to begin ACP, the lower their satisfaction rating from family members who felt that they had given up hope for the patient.<sup>12</sup> Early ACP ensures that the end-of-life care process for cancer patients is standardized, ensuring conversations begin and decreasing stigma around discussion of death.

Even if ACP occurs later in cancer treatment, many ethicists substantiate early introduction because beginning end-of-life discussions upon diagnosis of cancer also increases the likelihood that patient decisions are rational. Discussions can continue for months or even years through this process, allowing the patient to obtain sufficient information to make clear decisions about treatment options and talk about different aspects of their care decisions with family members and physicians. After cancer treatment, the psychological and emotional impacts of pain and suffering leave patients more likely to make decisions in distress, not fully elucidating or even knowing the options for their true preferences.<sup>13</sup> At the same time, as cancer becomes more serious family members tend to become more involved, many of whom pressure patients to continue treatment or agree to life-saving procedures that the patients themselves may not choose. According to a study from the National Cancer Society,<sup>14</sup> as cancer treatment progresses, family-controlled decisions increase from only 1.5% to almost 20% of decisions and decisions labeled “equally sharing” encompassed almost 60% of advanced cancer treatment choices. Meanwhile, family members were significantly more likely than patients to speak positively to oncologists about continuing invasive cancer treatment,<sup>15</sup> exhibiting their motivation to change patients’ decisions. Due to these factors, this perspective argues that early ACP at outpatient visits is essential to allow patients

to make informed independent decisions.

Finally, scholars who argue for the initiation of ACP as early as possible explain that beginning ACP can initiate discussions about life goals, wishes, and desires that can improve life even before end-of-life care is necessary.<sup>16</sup> In La Crosse, Wisconsin, for example, ACP was standardized through a report entitled “Respecting Choices Advanced Care Planning,”<sup>17</sup> requiring all patients to fill out an advanced care directive upon entering any doctor’s office or hospital. Because of this, 96% of adults in the city have an advanced care directive, and almost all of individuals with an advanced care directive have reported at least 3 conversations with a family member regarding their end of life choices.<sup>18</sup> Patients remarked in an analysis of the change that these discussions often quickly diverged from end-of-life preferences to desires and wishes that they wanted fulfilled before reaching that stage, such as travel, more time with family, and other personal goals.<sup>19</sup> Reflection upon current life, in addition to improving ACP discussions and rationality, provides evidence for the perspective that ACP should be implemented at outpatient visits directly after diagnosis of cancer.

#### **Timeline 2: Terminal Cancer**

Although traditional ACP may be moving toward earlier implementation, some scholars argue that cancer ACP should be initiated at a later stage due to the distinct differences between cancer patients and the general population. Cancer ACP is recognized as significantly distinct from traditional end-of-life care, particularly due to the unpredictable nature of the disease and numerous treatment options available. Beginning ACP too early may signal that a doctor does not have hope for the current method of treatment, potentially isolating patients and family mem-

bers, or emotionally overwhelm a patient attempting to cope with the implications of a cancer diagnosis.<sup>20</sup> Thus, these scholars argue that cancer ACP needs to be initiated more carefully than traditional end-of-life care discussions with Medicare or other generally healthy patients. To balance seriousness of illness with rational decision-making capability, scholars of this perspective argue that ACP should begin when cancer is labeled terminal, also known as end-stage or advanced cancer. Describing cancer as “terminal” expresses that the patient will have six months or less to live if the disease continues its current course.<sup>21</sup> This timing postpones ACP until it is required prior to potential end-of-life decisions.

The main reason that some scholars argue that physicians should wait to initiate ACP until terminal cancer diagnosis is the resistance of cancer patients at earlier stages to honestly discuss end-of-life care. Unlike Medicare patients with chronic illnesses, cancer patients are of all different ages and stages of life, making discussion about end-of-life planning considerably more difficult than with older patients naturally approaching death. Patients in their twenties and thirties diagnosed with breast cancer may not be able to cope with their initial diagnosis at such a young age, let alone also be forced into ACP during early outpatient sessions. Many of these patients might also have considerable treatment options and potential for remission, questioning the necessity of ACP for these cases in the first place. In a study of advanced cancer patients published by the *Journal of Palliative Medicine*,<sup>22</sup> participants focused most on the psychological and social implications of ACP, noting that they would not agree to discuss these options until it was necessary. Over 60% of patients rejected ACP the first time it was brought up by their doctor, citing the fact that it was too early to begin discussions

---

about death.<sup>23</sup> Yet at the same time, patients recognized that cancer progression would force them to change their outlook on treatment: “If I progress...to another stage...I would...address a lot more of this.”<sup>24</sup> By deferring ACP until terminal cancer diagnosis, doctors can still provide hope and not overwhelm their patients while still ensuring that end-of-life discussions occur in a reasonable timeframe when necessary.

In addition to patient resistance to ACP at early stages, cancer ACP is arguably more effective when occurring closer to end-of-life care due to the patient’s familiarity with their foreseen circumstances. Many patients with terminal cancer have already gone through some type of cancer treatment and so can more clearly identify with the pain and suffering that certain end-of-life care might entail, allowing them to be more accurate about their wishes. Almost 70% of patients with advanced care directives prior to initial cancer diagnosis in a study by the *Journal of American Geriatric Society*<sup>25</sup> made changes to this directive after undergoing chemotherapy. Once terminal diagnosis is accepted, patients are also undergoing ACP in very close timeframe to the potential treatment, allowing for more accurate representation of patient choice at the time of the decision—accounting for changes in preferences and wishes based on how the patient’s life changed over the course of the disease. Familial and personal reflection will also be more honest and give consideration to all factors influencing the current decision, rather than theorizing about it as a future potential situation. According to a study from the National Institute of Medicine,<sup>26</sup> advanced cancer patients admitted to not fully discussing or understanding ACP decisions because at the time they did not believe that the cancer would progress to its current stage. Temporal and physical closeness to end-of-life care after cancer is

diagnosed as terminal allows for patients, families, and physicians to begin honest discussion about future treatment wishes and potential end-of-life options.

#### **Advanced Care Planning and Autonomy**

Both stances surrounding cancer ACP employ conflicting evidence of patient preference about timing of end-of-life care decisions. Because of the limited nature of this data, with less than 2,500 patients surveyed in each study on both sides of the debate, these inconclusive personal accounts will not be addressed in this essay as analysis of each timeframe. Instead, each argument will be evaluated against the goal of ACP noted in the first paragraph of the essay: autonomy of the patient. While true autonomy can never be achieved in end-of-life cancer care since patients will be unable to communicate competent decisions, autonomy through ACP intends to allow the patient to preemptively make decisions that he or she would want made at that time through advanced directives or instructions to a healthcare proxy.

Initiating cancer ACP under both conditions promotes autonomy in different, sometimes conflicting ways. Cancer ACP at initial cancer diagnosis advances autonomy of the patient by providing ample time for discussions and research about end-of-life treatment options. This extended timeline can allow patients time to not only read and talk, but also reflect before forced to make future decisions—the lower stress of decisions further away allows patients make clear, coherent choices. While ACP at terminal cancer diagnosis may occur later and not allow as much time for patients to make decisions or ask questions, this late initiation will also promote autonomy by allowing patients to make decisions that are more informed by their current state of life and potential past cancer treatments. Discus-

sions may also be more autonomous at this later stage because patients are more likely to understand the gravity of their ACP, encouraging deeper research and reflection. These competing claims underlie questions of autonomy and what is necessary for an autonomous decision.

Numerous medical articles outline key characteristics necessary for an autonomous medical decision: ample correct information, voluntary choices about interventions, assurance that the patient is competent to make the decision.<sup>27</sup> While neither significant time to make decisions nor proximity to the decision are defining factors on most major lists, ethicists have begun to debate the importance of “personhood” in autonomous health care decision-making. Dr. Rebecca Dresser, professor of Law and Ethics at Washington University School of Medicine, and other prominent ethicists, particularly those who study autonomy for values of Alzheimer’s patients, argue that because people change over the course of their lifetimes, advanced directives may be objected due to “the greater likelihood that the creator of the advanced decision would be ill-informed about his or her decision compared to the contemporaneous decision-maker.”<sup>28</sup> Medical advances and tolerance of past levels of pain and suffering are given as two examples that could alter personhood between ACP and their end-of-life treatment.<sup>29</sup> Although current medical ethics does not reject advanced directives made significantly prior to end-of-life, there has been general agreement that more contemporary advanced directives support autonomy.

With this ethical research in mind, the benefits of waiting until terminal cancer diagnosis for decisions about end-of-life care outweigh the benefits to extra time and lower stress of making end-of-life decisions early in the cancer treatment process. However, beginning ACP does not im-

ply that decisions must be made right at the beginning of cancer treatment; instead, integration of ACP only requires “communication between individuals and their health care agents.”<sup>30</sup> A combination of these two options, then, would be most effective in order to ensure autonomy of patients making health care decisions: an initial discussion during outpatient sessions introducing end-of-life care and providing end-of-life information with serious ACP and decision making deferred until necessary at terminal cancer diagnosis. Due to the preference of cancer ACP decisions during the terminal stage, however, if patients choose to ignore or deny initial ACP at outpatient sessions they should be allowed to wait until terminal diagnosis to begin these discussions so as not to repel the patient. This approach successfully balances promoting autonomy through both early information and contiguous personhood at the point of decisions.

While combining both approaches to cancer ACP may answer the question of best timeframe most successfully, it also implies necessary inquiry about ACP itself: particularly the nature of ‘communication’ between patients and physicians. What does this communication entail? Must decisions about end-of-life care be made to consider communication successful? Preliminary research into the definition of ACP finds that contradictory definitions muddle answers to these important questions.<sup>31</sup> Until ACP is more concisely defined, separating end-of-life discussions and decisions is necessary to ensure that patients remain autonomous and rational to make the most informed choices for their care and promote their dignity until death.

#### **Conclusion**

Through analysis of the two main bodies of research surrounding the timeframe of ACP for cancer patients, it is

clear that each perspective utilizes separate definitions of ACP: ACP as end-of-life discussions or end-of-life decisions. As the definition of ACP currently stands from the International Society of Advance Care Planning & End of Life Care, cancer ACP should begin as early as possible but ACP decisions must remain at terminal diagnosis to ensure correct moral personhood. As this combination conclusion indicates, however, ACP debates uncover ambiguous and changing definitions of ACP and autonomy. Recognition of these ambiguities, and clarification of outcomes, are necessary to better address quality of end-of-life care and ensure that patient choice is preserved as much as possible.

#### ENDNOTES

1. Institute of Medicine, "Committee on Approaching Death: Addressing Key End-of-Life Issues," *Dying in America: improving quality and honoring individual preferences near the end of life* (Washington D.C.: The National Academies Press, 2015).
2. International Society of Advance Care Planning & End of Life Care, "The definition of care planning" (2011). <<http://acpelsociety.com/acpdefinition.php>>
3. Centers for Medicare & Medicaid Services, "Proposed policy, payment, and quality provisions changes to the Medicare physician fee schedule for calendar year 2016" (Washington, D.C.: U.S. Government Printing Office, 2015). <<https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2015-Fact-sheets-items/2015-10-30-2.html>>
4. L. Levit, E. Balogh, S. Nass, P. Ganz; Edited by Committee on Improving the Quality of Cancer Care: Addressing the Challenges of an Aging Population, Board on Health Care Services, Institute of Medicine, "Delivering high-quality cancer care: charting a new course for a system in crisis" (Washington D.C.: The National Academies Press, 2013).
5. A.K. Narang, A. Wright, L. Nicholas, "Trends in advance care planning in patients with cancer: results from a national longitudinal survey," *Journal of the American Medical Association Oncology* 1.5: 601-608 (2015). doi: 10.1001/jamaoncol.2015.1976
6. Ibid, 603.
7. I. Harle, J. Johnston, J. Mackay, C. Mayer, S. Russell, C. Zwall, *Advance care planning with cancer patients: a quantity initiative of program in evidence-based care, cancer care Ontario* (Ontario, Canada: Program in Evidence-Based Care, 2008).
8. Atul Gawande, *Being Mortal: Illness, Medicine, and What Matters in the End* (New York: Metropolitan Books, Henry Holt and Company, 2014).
9. Narang, et al. 605.
10. S. Johnson, P. Butow, I. Kerridge, M. Tattersall, "Advanced care planning for cancer patients: a systematic review of perceptions and experiences of patients, families, and health care providers," *Journal of Psycho-Oncology* (2015). doi: 10.1002/pon.3926
11. Ibid.
12. Ibid.
13. J. Peppercorn, T. Smith, P. Helft, J. DeBono, S. Berry, "American society of clinical oncology statement: toward individualized care for patients with advanced cancer," *Journal of Clinical Oncology* (2011). doi: 10.1200/JCO.2010.29.2599

14. G. Hobbs, M. Landrum, N. Arora, "The role of families in decisions regarding cancer treatments," *Cancer by the American Cancer Society* 121.7: 1079-1087 (2015). doi: 10.1002/cncr.29064
15. Ibid.
16. Harle, et al. (2008).
17. Gunderson Health System, "Respecting Choices Advance Care Planning," Gunderson Health (2002). <[www.gundersonhealth.org/respecting-choices](http://www.gundersonhealth.org/respecting-choices)>
18. Gawande (2014), 134-5.
19. C. Joffe-Walt, "The town where everyone talks about death," *National Public Radio* (2014). <<http://www.npr.org/sections/money/2014/03/05/286126451/living-wills-are-the-talk-of-the-town-in-la-crosse-wis>>
20. B. Kiely, M. Tattersall, M. Stockler, "Certain death in uncertain time: informing hope by quantifying a best case scenario," *Journal of Clinical Oncology* 28.16: 2802-2804 (2010).
21. Harle, et al. (2008).
22. K. Barnes, L. Jones, A. Tookman, M. King, "Acceptability of an advance care planning interview schedule: focus group study," *Journal of Palliative Medicine* 21:23-28 (2007).
23. Ibid, 25.
24. Ibid, 26.
25. T. Fried, K. Bullock, L. Iannone, "Understanding advance care planning as a process of health behavior change," *Journal of American Geriatric Society* 57.9: 1547-1555 (2010).
26. Levit, et al. (2013).
27. J. Billings and E. Krakauer, "On patient autonomy and physician responsibility in end-of-life care," *Archives of Internal Medicine* 171.9: 849-853 (2011).
28. R. Huxtable and R. Meulen, *The voices and rooms of European bioethics* (London, UK: Routledge, 2015): 94-95.
29. Ibid, 95.
30. Institute of Medicine, "Committee on Approaching Death: Addressing Key End of Life Issues," *Institute of Medicine* (2015).
31. L. Emanuel, C. von Gunten, F. Ferris, "Advance care planning," *Archives of Family Medicine* 9.10:1181-187 (2000).

#### WORKS CONSULTED

- V. Entwistle, S. Carter, A. Cribb, K. McCaffery, *Journal of Geriatric Internal Medicine* 25.7: 741-845 (2010).
- M. Gillick, "Advance care planning," *New England Journal of Medicine* 350.1: 7-8 (2004).
- R. Sudore and T. Fried, "Redefining the "planning" in advance care planning: preparing for end-of-life decision making," *Annals of Internal Medicine* 153.4: 256-261 (2010).

# GUEST CONTRIBUTION

---

## SUSAN M. REVERBY, PHD

Author of “Examining Tuskegee: The Infamous Syphilis Study and its Legacy”

Susan M. Reverby is an historian and the Marion Butler McLean Professor in the History of Ideas and Professor Women’s and Gender Studies at Wellesley College. She is living proof you can get an undergraduate degree in the “wrong” field for yourself (Industrial and Labor Relations B.S. from Cornell) and still be in the humanities by getting an M.A. and PhD in American Studies. Her work has focused on women’s labor history, the history of nursing, race in medicine and public health, and ethics. Her latest book, which won three major awards, is *Examining Tuskegee: The Infamous Syphilis Study and its Legacy*.



---

## A N HISTORIAN WALKS INTO AN ARCHIVE...

It was supposed to be an ordinary day in the University of Pittsburgh’s archives in an industrial section of that city. I did not really need to be there, just following up another scholar’s footnotes on the kinds of studies on syphilis that were done in the 1920s. I was working on a second book about the infamous and well-known study in Tuskegee, where nearly 600 African American men (2/3 who already had late stage syphilis, 1/3 without the disease) were not treated but watched by the U.S. Public Health Service for four decades between 1932 and 1972. I did not find what I was looking for.

What I discovered instead was evidence of a then mostly unknown study, this one done in Guatemala in 1946-48, where sex workers, soldiers, mental patients and prisoners were actually *infected* with syphilis, gonorrhea and chancroid, but not told they were in an experiment nor properly treated. The study, run by an American physician who a decade later would also work in Tuskegee, was kept hidden away because it violated ethical norms at the time, even as the United States was prosecuting Nazi doctors in Nuremberg. There were thousands of pages of lab notes, hundreds of photographs, and multiple notebooks of correspondence. I took lots of notes. Then I did nothing for another few years as I finished my Tuskegee book, expecting this to be but a chapter.

It never made it into the book. It did make it into conversations with others, including David Sencer, the former director of the Centers for Disease Control who had been the CDC chief during the end of the Tuskegee Study. He read the paper I finally wrote up for me and asked if he could share it with CDC higher ups. The next few months were a whirlwind: a CDC epidemiologist went to Pittsburgh to look at the records, my paper and his report went up the chain of command, then to the National Institutes of Health, and finally to the White House and the State Department. On October 1, 2010, there was a formal federal apology to Guatemala from the Secretaries of State and Health and Human Services, a phone call from President Obama to the President of Guatemala, news coverage that spanned the world, and eventually reports from bioethics commissions in the U.S. and Guatemala

What I learned is you can never imagine what you will find in the archives. You can never know how the material will be used. You can never be sure how a story of medical misfeasance of this magnitude might lead to apologies, and hopefully more awareness of the arrogance of medical researchers who think they have the right to use whomever they need in the search of “truth.” And you never can predict how a simple walk into the archives can change your own understandings of how we need to oversee what happens in the name of research.



---

# PAPER BOATS, PAINTED STONES, AND PARKINSON'S

MEGAN LEE

On Saturdays you'd pick me up, and we'd spend the day playing and painting. You brought rocks to life with a few strokes of your paintbrush, transforming them into little woodland creatures or steepled churches as we ate Tootsie rolls and Werther caramels all day. Your sweet tooth was mine, though your artist's hand was not. My clumsy five-year-old fingers would move bright red paint over oblong stones to create what could almost pass for ladybugs, and you would smile and hold the messy product in your palm like it was a Monet or a Michelangelo. You taught me to fold paper boats out of newspapers, and filled the bathtub so I could watch them float, fill with water, and crumple into a wet mess. Do you remember?

I'd stand on your couch and admire your paintings on the wall, tracing images of trees, water, sunlight, and boats with my hands. I would pause over the portraits, sensing the love in each brushstroke - your likeness done by Grandma, and hers done by you - and I'd crawl into your lap so that I could match the laughter lines from your painted face to your skin. You'd show me pictures of myself as a baby, and tell me about how I would sleep on your chest, a tiny infant folded securely into her grandfather's arms, and asked me if I would remember these stories when you were gone. I didn't want you to talk about being gone. I wanted to paint stones and fold paper boats. At the end of the day you would take me home and kiss me on the forehead, and I'd wipe it away and give you a hug. I wish I hadn't wiped away those kisses. I hope you don't remember.

Your living room was filled with photos and paintings, with plants and papers you could never seem to throw away. Your packrat nature was mine, though your green thumb was not, and when you showed me paper boats you'd saved from years ago, I showed you the clumsy ladybug you'd helped me paint. I kept it on my desk instead of the plants that I could never seem to keep alive. We both remembered, and though we didn't go out every Saturday anymore, you still kissed my forehead at the end of each visit. I didn't wipe it away anymore, but I still gave you a hug, and you smelled of Tootsie rolls and Werther caramels. You didn't ask me to remember your stories when you were gone, but, a little older and a little wiser, I knew that your Parkinson's would take away your stories. I knew that soon it would be me telling you stories and asking you to remember.

When Grandma died, we all mourned, and remembered her as she'd lived. You had both struggled so much, your health and hers declining, but both of you stubbornly insisting that you'd continue to live together on your own in that little apartment filled with paintings and plants. Her body looked peaceful, and I believed her soul was at peace too. But at her funeral we both knew - that wasn't your wife, wasn't my grandmother. My grandmother was in the paintings and stories

---

and photos and memories. I've always been told I have her hands, and now at the end of every visit you clutched mine and gave them an extra kiss. Then you'd look at me, and mime cradling a baby on your shoulder, and I would smile so that you knew I remembered. When we went out to restaurants I would fold little paper boats out of the napkins, and you would nod approvingly, proud that I had remembered. I hated to think that you wanted me to remember for when you were gone. I just wanted to remember you for your paper boats and painted stones.

My visits got fewer, and your strength grew less. You fell more often, you forgot more often, you called and I avoided your calls because your words would slur through your dentures and I wanted to remember when you would tell me stories and take me out every Saturday, not when you could barely walk a lap around the house or feed yourself without your hands shaking. Your laughter lines remained, but new lines appeared - lines of pain, lines of age, lines that carved their way into your skin that was not the skin I remembered tracing years ago. But it was still you beneath the skin, still you behind the cloud of Parkinson's that made you forget. I wish I'd taken your calls or written you letters. I wish I'd reminded you that I remembered.

Parkinson's makes you forget, but you always remembered my name and my face. You forgot where you left your little battery-powered radio, but you remembered your love for art and music. You forgot where you left your glasses and your hat, but you remembered making paper boats and holding me as I slept. You forgot how much time lapsed between my visits, but you remembered holding my hands as I tried to walk before I could crawl, and you remembered taking me out every Saturday years ago. You tried telling me stories again as I pushed your wheelchair up and down the halls of the nursing home, and I tried to listen and remember, because deep down I knew soon that would be all I had left. And at the end of every visit, you still kissed my forehead and I still gave you a hug. You smelled of medicine and sweat instead of Tootsie rolls and Werther caramels, but I still gave you a hug, and then I'd tell you I loved you and that I'd see you next time.

But next time was always far away, and while I was far away at school my next chance for next time disappeared. When I found out I folded a paper boat and I cried and I remembered. The next time I went home I couldn't bring myself to visit your grave, couldn't bring myself to think about the freshly turned plot of earth next to Grandma's, because you aren't there either. You are in every paper boat I fold and every memory I hold. You are in the little bamboo plant that now flourishes on my desk in place of the painted ladybug. So I won't mourn you, because I can't admit that you're gone. I just fold paper boats and collect stones to paint for next time. I eat Tootsie rolls and Werther caramels, and I remember.



---

# A NXIETY

SARAH RAMSEY

Is when I am looking inwards through a thin narrow tube,

Trying to read letters on a faraway poster through the hole.

The doctor is waiting impatiently for my answers,

His team of interns looks intently at me then scribbles back on their notebooks.

The tube is skinnier than a straw.

I don't know why I picked it up,

It seemed like the most logical instrument to help me see more clearly.

As I squint, and squint, the letters become blurrier, and blurrier.

I hear ferocious writing, tapping of feet, and the tick tock of a clock.

My eyes start watering, and a tear falls in the straw.

Blocking any chance of vision I might have had.

Suddenly, as the tear drop falls through the other end,

The room goes silent,

The lights dim,

And the tube turned out to be nothing more than a pencil.

I tuck it behind my ear,

Read the letters on the poster.

And walk out of the room.

---

# MENTAL ILLNESS: THE MYTH OF FULL RECOVERY

SHERRY HSIAO

I know the way to the basement of Gasson all too well.

That familiar shame each time I walk through those semi-transparent glass doors, a shame that becomes just a little less noticeable with each visit but never truly goes away. Just like any other basement, this one makes my nose stuffy, my head dizzy, and my mind claustrophobic. But the urge to get out of this basement is so much more than to avoid the physical discomforts of my body.

It's shame.

It's a shame that as a Psychology major I know I should not feel, but I feel it every single time.

Most days, I can march across the upper floors of Gasson to my classes and pretend I don't know where those poorly lit stairs lead. Most days, I can pretend I'm only in the basement for the vending machines that only work half the time. But my nervousness and the familiarity with which I stroll through the oddly arranged floor as if it were my second home give me away.

Criminals are people with something to hide. I'm not a criminal. My suffering is not a crime.

So why am I hiding?

...

In the historic debate between Dr. Albert Ellis and Dr. Thomas Szasz on the topic of whether mental illness is a fact or myth, Szasz argued that mental illness is a metaphor.

In the two and a half hour debate that occurred in 1977, Szasz stated, "The hysteric fakes illness, just like the psychiatrist fakes doctoring!" He argued against involuntary institutionalization, a medical model of psychiatry, and the use of diagnostic systems such as the *Diagnostic and Statistic Manual of Mental Disorders* (DSM) that is widely used today. Szasz claimed

---

that naming a condition a "disease" implies that it will still be present after death. Yet at the time, there appeared to be no convincing biological trace of mental illness.

During the heated debate, his opponent Ellis called his ideas "crooked thinking." Ellis argued that there is a biological basis for mental illness. He supported the institutionalization of people with mental illness, warning the scientific field that the consequences of not doing so outweigh the costs.

One thing that both psychologists agreed on is that individuals labeled as having mental illness and the term "mental illness" itself have been abused.

To this day, an individual who has recovered and no longer exhibits enough symptoms to meet the criteria of a depression diagnosis is still labeled as having depression "in remission."

The stigma is permanent.

The prevailing clinical practice today anticipates that the mental illness will return.

It is this kind of practice that reinforces the underlying belief that having mental illness is a disadvantage.

...

In "Three Spheres," the final essay of the extraordinary memoir *Welcome to My Country*, the psychologist and writer Lauren Slater describes the haunting presence of her history of schizophrenia: "*I am not* that girl any longer. I tell that to myself as I ride up the hospital's elevator. I *found* some sort of way into recovery. But I know, have always known, that I could go back. Mysterious neurons collide and break. The brain bruises. Memories you thought were buried rise up."

Slater expresses a fear of relapse that is common to even people who have fully recovered for years. Moreover, her honest narrative raises questions about the curability of mental illness.

The DSM-5, which was released in 2013, suggests that there is a magical number of symptoms that separates individuals with and without mental illness. Exhibit "five or more" and you're considered depressed.

But who teaches you how to deal with the aftermath of having been diagnosed with a mental illness?

How will you convince yourself that any subsequent happiness is real and not merely a high point on the unpredictable curve that represents the ups-and-downs of mental illness?

---

Will you believe that the happiness you're experiencing is not just a temporary state of a good feeling that could be taken away at any moment?

...

Some people, like the Nobel Prize-winning mathematician John Nash, have learned to live with their mental illness. Nash, whose struggles with mental illness are captured in the film *A Beautiful Mind*, suffered from paranoid schizophrenia for years before losing his life in a car accident in 2015.

In the artistic world, the public has long held a belief in the link between intelligence, creativity, and mental illness, although science is still in the process of proving its biochemical origin. Writers, painters, and musicians who have experienced episodes of mental breakdown have long been known for their extraordinary sense of creativity and imagination. At the same time, it is often their keen insight and sensitivity to the world around them, as well as their hyperawareness towards their inner mental lives, that troubles them in deeply disabling ways. It has been widely established that Emily Dickinson showed signs of manic depression, Vincent van Gogh committed suicide, and Beethoven likely suffered from bipolar disorder. Full recovery might have inhibited their ability to pursue and excel in their areas of passion. Mental illness becomes a double-edged sword—both a burden and an advantage.

The unexpected benefits of suffering from mental illness make it all the more difficult to fight a battle in which the victim is already on the losing side. Treating mental illness itself requires enormous levels of dedication and commitment. It is one thing to be unmotivated to treat an illness that is hard to overcome. But how do you begin to justify removing a part of yourself that is considered good?

If suffering becomes a sort of addiction, then mental illness is the drug.

The various forms through which mental illness compensates for its devilish acts—through granting creative imagination, through providing stimulation in otherwise dull mental lives—trick the victim into repeating or remaining in the worst of mental conditions.

...

The American Psychological Association (APA) defines addiction as “a condition in which the body must have a drug to avoid physical and psychological withdrawal symptoms. Addiction's first stage is dependence, during which the search for a drug dominates an individual's life. An addict eventually develops tolerance, which forces the person to consume larger and larger doses of the drug to get the same effect.”

In the case of an attachment to suffering, the withdrawal symptoms would be a perceived loss of creativity and intellect.

---

The stage of dependence would occur when the artist engages in self-injurious behavior that dramatizes or worsens the symptoms of the particular mental illness. The stage of tolerance would be resembled by the point in the course of the disease when the artist no longer recognizes the abnormality of his or her suffering and becomes comfortable with accepting it as a permanent part of his or her life.

Applying a different analogy, developing an addiction to mental illness would be like experiencing Stockholm syndrome.

According to APA, Stockholm syndrome occurs when “hostage survivors often develop an unconscious bond to their captors and experience grief if their captors are harmed. They may also feel guilty for developing a bond.” Thus, like the hostage who falls in love with his captor, the patient falls in love with his or her mental illness.

This love for a source of pain is reminiscent of Sigmund Freud's writings on masochism and repetition compulsion. An illusion is created in which the victim believes that if he or she could only experience the pain again, he or she can relive the ecstasy that is recovery. It is what draws the victim back into the dark cages of mental illness time and time again.

It is for the highs that come with the lows.

...

Some researchers have attempted to outline the benefits of having depression. In a 2009 *Scientific American* article “Depression's Evolutionary Roots,” evolutionary psychologists Paul W. Andrews and J. Anderson Thomson describe depression as an evolutionary adaptation. They write, “Analysis requires a lot of uninterrupted thought, and depression coordinates many changes in the body to help people analyze their problems without getting distracted.” In line with better analytical skills, Andrews and Thomson also highlight a stronger ability at solving social problems in people under more depressed states.

From a more medical perspective, in a 2012 *Atlantic* article “The Evolutionary Advantage of Depression,” author Brian Gabriel summarizes physicians Andrew Miller and Charles Raison's proposal of a “smoke-detector principle” which allows the body to prepare the immune system for acute stress. Miller and Raison hypothesize that “some of the alleles (forms of genes) that increase one's risk for depression also enhance immune response to infections.”

Thus, when the body detects signs of acute stress, the accompanying depressive symptoms such as “social withdrawal, lack of energy, and a loss of interest in once enjoyable activities” serve to reduce the harmful consequences of the infection. These evolutionary benefits of depression provide an explanation for why depression can be a positive and adaptive response to physiological and psychological stress.

These studies suggest that like the sickle cell gene that provides immunity against malaria, mental illness has its perks.

---

• • •

Adjusting back to “normal life” can be difficult. It can often involve seemingly perpetual cycles of recovery and relapse. Especially for those who have come to identify the positive effects of their mental illness, letting go of those desirable mental states can be a challenging process of constant self-reassurance and logical reasoning.

In her autobiographical novel, Slater exemplifies the kind of complexities found in people’s relationships with their mental illness. Her struggle to maintain a healthy balance of understanding the patient but not relating too much, of using her experience but not appearing so insightful as to betray her own history reveals an inherent flaw, if not hypocrisy, in psychotherapy and clinical psychology.

In the same essay cited above, Slater writes:

But of course I won’t say such a thing, wouldn’t dare, for I would lose my credibility. But the funny thing is, I’m supposedly in a profession that values honesty and self-revelation. Freud himself claimed you couldn’t do good analytic work until you’d “come clean” with yourself in the presence of another... At the same time, though, another more subtle yet powerful message gets transmitted to practitioners in the field. This message says, Admit your pain, but only to a point. *Admit it but keep it clean. Go into therapy, but don’t call yourself one of us if you’re anything more than nicely neurotic.* The field transmits this message by perpetuating so strongly an *us* versus *them* mind-set, by consistently placing a rift between practitioners and patients, a rift it intends to keep deep.

This rejection of the very values she attempts to teach her patients and the gap between theory and reality in both research psychology and psychotherapy contributes to the failure of modern society to de-stigmatize mental illness.

On a separate note, Slater’s incredible insight into mental illness also suggests that a history of treatment or a high level of understanding of the self and the anxieties of daily life—verging on self-analysis—can be beneficial to the profession of psychotherapy.

Slater excels in her communication of the experience of schizophrenia because she has experienced it firsthand. Moreover, it is her ability to understand what her patients are going through that allows her to show empathy, which is crucial to the therapeutic relationship.

To deny Slater’s professional judgement because of her history of schizophrenia is to stigmatize all professionals who have struggled with mental illness. This denouncement suggests that there is nothing to be gained from different perspectives,

---

and suggests an inherent flaw in the judgment of individuals who have experienced mental illness—even those who have recovered. This stigmatization contributes to the list of reasons many people hide this part of themselves.

• • •

In the final scene of director François Truffaut’s 1959 French film *The 400 Blows*, the young protagonist Antoine Doinel runs to the ocean, a place he has always wanted to visit. At this point, he had been sent away to a center for delinquent adolescents after a series of emotional setbacks. The psychologist at the center proves to be unhelpful.

Like Antoine’s ocean, the social construct of mental illness is similarly fluid. While pain and suffering are real, the categories, symptoms, and prognoses of mental illnesses are less clearly visible and defined, despite what the DSM-5 might suggest.

Perhaps it is foolish to even speak about full recovery. Perhaps it is best to imagine the development of mental life—in spite of the flashbacks and pauses and dreams—as a tape you cannot unwind.

Knowledge cannot be reversed. Treatment, medication, and therapy may remove the symptoms of mental illness to an un-diagnosable degree, yet the impact that going through that kind of suffering creates cannot be forgotten. It is as if a new neural pathway has been created in the brain to commemorate the survival and mourn the suffering.

• • •

Gasson 001 isn’t the most pleasant place to be, but it feels familiar.

The way we compose ourselves is almost an art. We greet the receptionist’s sympathy with a professional smile that says, “I’m okay. No really, I’m fine.” We greet the other clients with a silent, half-complete smile that shows that we recognize each other’s pain. Then we proceed to avoid eye contact with everyone altogether until our name is called all too loudly, the sound waves bouncing off the narrow walls to provide us no protection as we make our way towards the doctor. This is a universal art that, like riding a bike, you never forget.

We’re all a little mad in our own peculiar ways.

It is our discontent with our lives and the realization of the human condition that drives creativity, change, and yes, sometimes mental illness.

---

#### WORKS CONSULTED

American Psychological Association, "Addictions," American Psychological Association (9 September 2016). <[www.apa.org/topics/addiction/](http://www.apa.org/topics/addiction/)>

American Psychological Association, "Adjusting to Life After Being Held Hostage or Kidnapped," American Psychological Association (July 2013). <[www.apa.org/help-center/hostage-kidnap.aspx](http://www.apa.org/help-center/hostage-kidnap.aspx)>

American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (2013).

Paul W. Andrews and J. Anderson Thomson Jr., "Depression's Evolutionary Roots," *Scientific American*, (25 August 2009). <[www.scientificamerican.com/article/depressions-evolutionary/](http://www.scientificamerican.com/article/depressions-evolutionary/)>

Albert Ellis and Thomas Szasz, "Mental Illness: Fact or Myth?" Rockville Center, New York, Debate (30 October 1977).

Brian Gabriel, "The Evolutionary Advantage of Depression," *The Atlantic* (2 October 2012). <[www.theatlantic.com/health/archive/2012/10/the-evolutionary-advantage-of-depression/263124/](http://www.theatlantic.com/health/archive/2012/10/the-evolutionary-advantage-of-depression/263124/)>

Lauren Slater, *Welcome to My Country* (Random House, 1997).

François Truffaut, *The 400 Blows*, Les Films du Carrosse (1959).



---

# FACELESS

SOPHIA IHLEFELD

Megan Meier had never been so happy. Just weeks before her fourteenth birthday, a boy named Josh Evans requested to be friends on Myspace. Megan didn't know Josh, but he was sixteen years old and wanted to talk to her regularly – become her friend. She begged her mother to let her add the “hot” boy. Though they never met in person or even spoke on the phone, the two teenagers began to exchange messages consistently.

“Megan had a lifelong struggle with weight and self-esteem, and now she finally had a boy who she thought really thought she was pretty,” says Megan's mother Tina. This was a real relationship to Megan, although it never surpassed words on a screen. Josh aside, Megan had lost twenty pounds, had just begun playing volleyball at a new school, and had been seeing a therapist for years to help level out her depressive urges.

Josh opened up to Megan, and she did in return. She described herself “M is for modern, E is for enthusiastic. G is for goofy. A is for alluring. N is for neglected.”

Only a matter of weeks later, Josh's tone began to change. He began by saying that he didn't want to be friends with Megan anymore, claiming that he “heard that you are not very nice to your friends.” Over the next days his messages continued progressing in their malice.

Josh also began sharing the messages Megan had sent him

to other kids at her school, who then began sending her vile messages and creating bulletins entitled, “Megan Meier is a slut. Megan Meier is fat.”

Josh finally concluded with, “The world would be a better place without you.”

Megan Meier hanged herself in her bedroom closet in October 2006, twenty minutes after reading these words.

Megan is one of countless teenagers who've fallen victim to the dangers of social media. The Internet provides a screen behind which immature, vindictive, and sadistic users can hide and escape the consequences of their actions. The Meiers later discovered that Josh Evans was not a real person, but had been created as a ploy to make fun of Megan.

Josh Evans was really two people, the adult parents of a girl with whom Megan used to be friends.

The nuances of mental health concerns and their causes are too many to number, but analysts have noticed a trend over the past decade that indicates a new trigger for mental illness. The introduction of social media as a crucial element of young adult lives has led to higher depression and suicide rates, especially among women. There has been a positive correlation between the popularity rise of social media sites - such as Facebook, Twitter, and Insta-

gram - and the steady increase of suicides in teenagers and young adults.

Offered an illusion of community and even of reality by social media sites, young adults are weighed down by a feeling of inadequacy. This leads to depression and the belief that they are the only ones suffering in their communities. Social media sites also offer both information and incentive to bring a violent end to this pain and confusion; they normalize such behavior while simultaneously providing a new internet-provided method of harassment. It is important to explore the ways in which social media has in fact helped to counteract this trend and improve mental health, as well as how society as a whole can respond to this potentially sinister root of depression, anxiety, and self-destructive behavior.

According to the Centers for Disease Control and Prevention, suicide is the third leading cause of death for teenagers and young adults ages 15-24, preceded only by “unintentional injury” and “malignant neoplasms.” It seems that as social media expands, so does the death count, as well as the number of teenagers whose mental health is adversely affected. Research from David Luxton, Jennifer June, and Jonathan Fairall's article “Social Media and Suicide: a Public Health Perspective” reports that Facebook alone reports thirty billion pieces of content on average is shared every month on its site. That leaves copious amounts of room for questionable and potentially dangerous content. The sorts of content that users can get away with is incredible.

An example of this manipulation of social media comes in the form of a girl from my hometown, who I'll call Kelly. At age fourteen, Kelly's best friend texted her worriedly, informing Kelly that there was a video being forwarded

around their school and that people were claiming Kelly was the star. The video featured a girl with long blonde hair, like Kelly, masturbating with her back facing a mirror.

Kelly immediately informed her parents, telling them frantically that it was not her in the video. They contacted the police in an attempt to root out the original sender, but the video had been forwarded so many times that there was nothing law enforcement could do. Even though her family and friends helped spread the truth, the damage had already been done to Kelly's reputation and psyche.

Later in the school year, Kelly's attention was drawn to a new website created in her name. A picture of Kelly clad in a bikini, taken from her Facebook page, was the web page's main avatar. The blurb on the page encouraged boys aged 10-13 to contact “her,” send pictures, and post videos of themselves undressing on this website. The ploy even got one ten-year-old boy to film himself undressing till he stood bare in front of the camera, dressed only in his underwear. Also posted on the website was a video of Kelly and two girl friends from Kelly's pool party, lounging in the hot tub together. Kelly had not been aware she'd been filmed that day, but the video's caption claimed she and her friends had been “doing things” to each other.

This time, the police were able to trace the IP address back to the original computer; a boy from Kelly's school had been using her as a disguise on social media in order to humor his sexual deviancy. He was arrested but released the next day after his parents posted bail, and has yet to see any real consequences.

This boy now goes to public school with my little sister.

---

Kelly is thankfully free of her classmate's manipulation, but has suffered severe depression in the aftermath. Her family and friends are behind her during her healing process.

The amount of unrestricted content released per year is also an indication of how not only popular, but essential, social media has become in the modern age. With the exception of schoolwork, or perhaps reading the news, the majority of time teens spend on the Internet involves sites such as Facebook, Myspace, Twitter, and Youtube. They keep track of their "friends" lives, desperately craft and maintain a picture-perfect profile of their own, and attempt to "connect" with the outside world.

The journal *Pediatrics* notes, "According to a recent [2011] poll, 22% of [American] teenagers [access] their favorite social media site more than 10 times a day, and more than half of adolescents log on to a social media site more than once a day... Thus, a large part of this generation's social and emotional development is occurring while on the Internet and on cell phones."

The 2013 Ontario Student Drug Use and Health Survey, from Ottawa Public Health, asked 753 students in 7th through 12th grade to answer how much time they spent daily on social media, as well as to describe any symptoms of mental illness and any treatment they were currently getting, if any at all. This survey found that teens who access social media sites for two or more hours are statistically and considerably more likely to experience "poor mental health, psychological distress and suicidal thoughts."

According to the National Institute of Mental Health, in the year 2011 about 2.2 million, or 9.1% of teenagers in the United States suffered a minimum of one major de-

pressive attack. Furthermore, a national survey indicated almost one third of teenagers in the U.S. satisfy the criteria for an anxiety disorder. In addition, "Some 5% to 8% of U.S. teens attempt suicide yearly, with an additional 16% seriously considering suicide within the past 12 months. Approximately 157,000 kids age 10-24 are treated in emergency departments every year for self-inflicted wounds... Victims of cyberbullying are almost twice as likely to have attempted suicides compared with adolescents who were not the target of online attacks."

Perhaps this is the reason that a child must be thirteen years or older to make an account on a website without parental permission, as dictated by Congress in the Children's Online Privacy Act. The official purpose of the law is to make websites unable to collect information on children younger than thirteen, but this is also inextricably linked to the issues to be discussed further in this essay. The information that social media sites collect and make public can be used against an individual, fueling cyber-bullies and other harassment and leading to psychological affliction. According to *Pediatrics*, other issues social media and the Internet spark are Internet addiction and coexisting sleep deprivation.

While the cause of this increasing percentage of teen suicides cannot be proven, its correlation in some respect to social media use is undeniable. It is likely, though, that the correlation is not one sided. As suggested by Carolyn Greig in an article for *The Huffington Post*, young adults struggling with mental health may be naturally inclined to use social media more frequently, in addition to the excessive use of social media contributing to poor mental health of the average adolescent.

---

Lui Yi Lin, graduate student at the University of Pittsburgh School of Medicine and a lead author of a study: Social Media Use Associated with Depression Among U.S. Young Adults, asserts that "People who already are depressed are turning to social media to fill a void" which clearly cannot be filled by a computer screen or its largely fabricated contents.

Dr. Hugues Sampasa-Kanyinga supports this sentiment, saying that adolescents struggling with mental illnesses turn to social media "to satisfy unmet needs for face-to-face mental health support." These young adults feel isolated and that no one will understand. Profiles on social media, however, make it easier for these teenagers to feel a sense of connection without having to leave the comfort of their bedrooms.

Perhaps the most explicit term for this phenomenon, explained in *Pediatrics*, is "Facebook Depression" which is the occurrence of depressive symptoms after a teen spends excessive amounts of time on social media sites like Facebook. The element of social media that is the most likely cause of Facebook Depression can be linked to social psychologist Leon Festinger's 1954 "social comparison theory", which postulates that human beings attempt to determine their own worth based on their comparison to others. The ready availability of so many flawless profiles on social media, accessible on phones that teenagers carry every day, makes the barrage of comparisons and the possibility of resulting self-deprecation constant and nearly inescapable.

Even if a teen becomes self-aware of his or her depression, *Pediatrics* describes how further exploration of symptoms on crude sites and blogs for "help" may unintentionally lead to promoted substance abuse, unsafe sexual activity,

or aggressive and self-destructive actions. *Anyone* can give "advice" and instruction for someone's depression, rather than certified clinicians and specialists alone. Basically, once a teenager becomes too involved in social media and the lures of the Internet, it becomes extremely difficult to extricate him or herself from its clutches. Even if they realize and acknowledge that something is wrong, the online sources to which they run for help could only exacerbate the problem.

University of Pennsylvania student Madison Holleran fits the description of a young adult suffering from Facebook Depression. Madison loved her family, performed well academically, and ran track at UPenn after exhibiting her exceptional athleticism in high school.

When the college environment proved more stressful and overwhelming than she imagined, Madison was at a loss for what to do. All of her friends around her seemed to be perfectly fine, posting beautiful pictures on Facebook and Instagram that depicted their flawless lives. Although Madison maintained social media profiles just like these, her older sister Ashley says that Madison confided her belief that her social life was inferior to those other girls'. Everyone else is making more friends, going to crazier parties, taking prettier "selfies," eating better food, and participating more successfully in the dating scene.

Because she believed no one would understand, she kept up her own facades on social media, so much so that no one knew how truly, deeply depressed she was, or could expect what she would do next.

At nineteen years old, on a brisk January evening in Philadelphia, Madison Holleran jumped off the ninth level of

---

a parking garage. There was almost no blood; a passerby who found her did not even realize at first that the young woman had done anything but lie down for an alcohol-induced nap.

Just an hour before taking her flying leap off of the parking garage, Madison posted one last photograph to Instagram. It showed the trees of Rittenhouse Square, holiday lights twinkling in the branches. A perfect picture for a picture perfect girl.

Madison Holleran's suicide is an unfortunate but accurate representation of Facebook Depression, and the double lives that so many adolescent girls live. Social media is supposed to bring friends and the world together, but can unintentionally lead to a greater sense of isolation and helplessness than anyone could have imagined. "This generation is alone. They have 1,000 friends, but they are alone," says Adam Doynes, a certified biblical counselor specializing in adolescent patients, to *WORLD* magazine.

Gregory T. Eells, Cornell University's Director of Counseling and Psychological Services, is a steadfast believer in the power of Facebook Depression. He notes that social media can support a student's belief that he or she is the only person suffering on campus. His patients claim during counseling that everyone around them look content with their lives.

In response, Mr. Eells says, "I walk around and think, 'That one's gone to the hospital. That person has an eating disorder. That student just went on antidepressants.' As a therapist, I know that nobody is as happy or as grown up as they seem on the outside."

The substitution of social media for real meaning in life, which leads to depression and consequently cheapens an individual's general value of life, is not the only way in which social media use can lead to teen suicide. Cyberbullying, defined by *Pediatrics* as "Deliberately using digital media to communicate false, embarrassing, or hostile information about another person," is the most common online risk for all adolescents. This, according to U.S. Legal Definitions, could be as minor as posting rumors or gossips about a person online, therefore causing animosity in the minds of others, or as antagonistic as personally labeling a victim and publishing materials that would brutally denigrate or embarrass him or her. Cyberbullying is intentional and repetitive, often including threats, personal humiliation, and harassment.

A JAMA Pediatrics study showed that twenty-three percent of teens report that they are currently, or have in the past been, the target of cyberbullying. Fifteen percent admitted to being the bully themselves. The researchers explored the connection between social media victimization and depression, showing "without exception – a significant correlation."

Cyberbullying, when connected to suicide in any way, is called cyberbullicide. A survey given to about two thousand middle school students showed that victims of cyberbullying were nearly two times as likely to attempt suicide than those who were not. Interestingly, the results also indicated that cyberbullies were 1.5 times as likely to attempt suicide. These results are indicative of what an unhealthy environment social media is for all parties involved. The Luxton/June/Fairall article states that "Although cyberbullying cannot be identified as a sole predictor of suicide in adolescents and young adults, it can

increase risk of suicide by amplifying feelings of isolation, instability, and hopelessness for those with preexisting emotional, psychological, or environmental stressors."

Ryan Halligan was one such victim of cyberbullying. He is tragically just one in a staggering statistic of cyberbullicide victims, but it is important to remember Ryan and his story.

Ryan didn't know until middle school that not everybody struggled like he did. Words and speech sometimes got all jumbled up in his head, so learning them was a little bit slow, and it took him a while to figure out just how his body was supposed to work. Later he'd learn that technically he had stunted speech, language, and motor skill development.

Although he had difficulties in school because of these disabilities, his parents enrolled him in special education services so that he would have as good a chance in the world as any other little boy. They described him as lanky, sweet and gentle; he was hard on himself when his grades weren't as stellar as he'd wanted.

Beginning in the fifth grade, and continuing all throughout the next three years, Ryan was targeted by another student at his school, along with this boy's friends. They taunted him regarding his reduced physical coordination, but since they never laid a violent hand upon Ryan, Ryan's parents couldn't do much. They sent him to therapy to discover coping mechanisms, which seemed to work.

When the bullying continued, however, Ryan begged his parents to switch schools or be home-schooled. He hated going into that middle school building every day, constant-

ly looking over his shoulder. When his parents explained how neither of those options were possible, Ryan said he at least wanted to learn how to defend himself. The Halligans agreed, helping Ryan train with a "Taebo" kickboxing set.

One day in February 2003, Ryan had his opportunity. He fought back when the bully hit him, and proudly claimed that he was "able to get in a few good punches" before the principal broke up the fight. Ryan was confident he wouldn't have issues with the bully anymore. In fact, within the next month they'd even become friends. His parents were extremely hesitant about this new development, but decided Ryan was old enough to make his own decisions.

Elated to have made a friend out of an enemy, Ryan shared a somewhat embarrassing personal story with the ex-bully, wanting to laugh with him about it. Ryan's new "friend" used this information to spread a vicious rumor online that Ryan was gay. He was taunted relentlessly, bullied during the school day and then immediately barraged by sneers again when he started up his computer at home.

That summer, Ryan attempted to become friends with another girl at his school online, in what his parents believe was an attempt to prove his heterosexuality. The girl was kind and funny, not to mention the most beautiful and popular girl at his school. They struck up a friendship online over the summer of 2003, during which she encouraged Ryan to open up to her, because she was, after all, his girlfriend. Ryan was so happy to be talking to her that it made all of the online harassment seem less suffocating.

At the commencement of the new school year, Ryan approached the girl for the first time in person, smiling and



---

still a bit shy. She, with her friends gathered around in the most stereotypical mean-girl fashion, looked down her nose at Ryan with a cruel smile and told him that she didn't like him at all. He was just a loser, and she thought it would be funny to play around with him online.

That day the girl copied and pasted the private IM messages Ryan had sent onto the public forums their school viewed. Ryan's extreme humiliation now had an audience.

To put an end to the constant voices whispering and taunting in his head, made visible on a screen whenever he logged online, Ryan Halligan hung himself in the family bathroom on October 7, 2003.

The positive correlation between social media and suicide among teenagers like Megan Meier, Madison Holleran, and Ryan Halligan is also due to the information on how to most successfully commit suicide the Internet provides. Luxton, June, and Fairall, explain how pro-suicide information, including detailed material on suicide methods, is easily accessible online. Forums and message boards on social media have been used to spread information on how to die by suicide, including knowledge of how likely one is to actually die by each method and how much agony is involved. For this reason, more adolescents are effectively killing themselves by gunshot or hanging, rather than conducting failed attempts through wrist cutting or overdosing.

Yet another startling phenomenon that social media has introduced is that of online suicide pacts. Online chat rooms can provide an easier way to share thoughts and feelings than doing so in person; most find it "safer" in certain respects, because they do not have to face physical rejection

or disparagement, and are speaking with those claiming to be suffering in the same way.

A suicide pact is an agreement between two or more people to die by suicide at a certain time and typically by the same lethal means. A cybersuicide pact is usually formed among complete strangers, unlike traditional suicide pacts. Sites for suicide pacts such as this are called "extreme communities," and they target those already emotionally and mentally vulnerable. Interactions among strangers through chat rooms or online forums have the potential to cultivate peer pressure to commit suicide and idolization of those who already have. Those who are currently indecisive about suicide may have their fears of pain or death assuaged.

Individuals have also begun leaving suicide notes online, on public pages. Seeing such material, if a viewer is feeling similarly, may make him become convinced that suicide is his answer as well. Rising popularity of video-sharing social media sites like YouTube have also contributed to this catastrophic phenomenon. With nearly entirely unrestricted content, suicide and self-harm videos uploaded for the public's perusal have the power to normalize such behavior.

Professor Lewis, Associate Professor in the Department of Psychology at the University of Guelph, examined the availability and substance of the most popular YouTube videos related to self-injury, including but not limited to cutting, burning, and hitting oneself. By typing in keywords such as "self-injury" and "self-harm" into the YouTube search engine, Lewis was able to access the fifty most-viewed videos featuring live individuals as well as the fifty most viewed non-character videos. The results of

---

this study showed that the top videos had over two million viewers and fifty eight percent of the videos had no viewer restrictions like a minimum age requirement.

In order to conduct this research in the most unbiased light, however, it was necessary to explore the ways, if any, social media can actually help *improve* mental health. While they certainly do not dwarf or even balance the dangers of social media, there are certain benefits to its use. For instance, Luxton, June, and Fairall explain that the routine nature of social media interaction has proven beneficial to children and adolescents; social media use can augment communication, social connection, and technical skills.

Although social media can provide triggering and unsafe material for adolescents, it can also make available suicide prevention materials. There are specific social networking sites for suicide prevention, which facilitate connections among peers with similar experiences to the suffering individual. As elaborated upon by Luxton, June, and Fairall, these sites spread awareness for "Prevention programs, crisis help lines, and other support and educational resources." Examples of social media sites like these include the National Suicide Prevention Facebook page and the American Foundation of Suicide Prevention Facebook page, both of which have followers by the thousands. Taking suicide prevention a step further, and indicating an awareness of social media's potential for disastrous influence, there is even a Facebook page: Report and Eliminate From Facebook Pro-Suicide Groups.

Other benefits of social media include health resources that are effortlessly and anonymously accessible, which can lead to, as stated by *Pediatrics*, "increased medication adherence, better disease understanding, and fewer missed

appointments." Students can also connect with each other on social media to work on schoolwork and group projects. Social media users are able to share their artwork with their communities, fostering their individual and collective creativities. Shared interests have the potential to bring together people from all races, sexualities, and socioeconomic backgrounds, which leads to greater social awareness and tolerance.

Upon reading all of the devastating statistics of depression and suicide correlated with social media use, parents and society as a whole ask themselves: What can we do? Firstly, it is important to understand the legal complexities involved, which makes only personal parental choices the truly plausible solutions.

Perhaps the most seemingly simple solution to the influence of social media on suicidal behavior is to create laws that ban content like that detailed earlier. Of course, judicial action could violate free speech and trespass on civil liberties. This makes it difficult to monitor or filter content created within the United States, for fear of breaking the First Amendment. In addition, it is doubly difficult to obtain jurisdiction over websites with international origins, as noted in Luxton, June, and Fairall's article.

The three scholars also note, interestingly, online social media has much fewer content-related restrictions than any other form of media. If a radio, television, or newspaper publishes questionable content, they risk losing followers and running out of business. Social media sites are decentralized, constantly changing and evolving, and thus do not run that risk.

Parental supervision, however, is not so limited. The

---

complete banning of social media from a household is not reasonable or effective. Instead, making sure more mental health resources are on the platforms adolescents are visiting, and making teenagers aware of them, is crucial. Dr. Brian Primack of Pitt's Center for Research on Media, Technology, and Health supports this, saying, "Because social media has become such an integrated component of human interaction, it is important for clinicians interacting with young adults to recognize the balance to be struck in encouraging potential positive use, while redirecting from problematic use."

Perhaps the greatest difficulty when dealing with this problem is the generational gap between parents and their children. Parents might not either understand the technology itself, or even their children's attachment to it at the base level. This makes it increasingly difficult to keep up with their children and the problems they face, as indicated in the stories of the Halligan and Meier families.

*KVC Health Systems* postulates that this problem can be alleviated not by an intensive technology course for all parents, but by the communication of five simple ideas to their children. The first is that a person's online profile might not be an accurate representation of his or her life. They may be masking their own mental illness, or worse, pointed malice. Everyone always posts the best parts of their lives, not the worst.

Secondly, there is a difference between an ideal and a real life. Every teenager is seeing the same content, and every one feels inadequate when faced with the seemingly perfect lives of their friends. A life does not need to be perfect to be worth living.

Thirdly, an individual's real self can be aligned with their ideal self, with the right motivation. The key is to transform hopeless fantasies into obtainable goals. Another tip for a parent is to be open and vulnerable about his or her own past. Communicating prior struggles can show a child that he or she is not alone.

Lastly, remind them of their best attributes. It is easy and habitual for self-deprecating teenagers to focus on their flaws rather than their assets. With these tips, perhaps the world won't seem so isolating to social media-navigating teens.

While social media is not the worst thing to happen to American adolescents, because of the few ways it can help their mental health, it is definitely not a resource to be used without caution. All research completed on the subject has shown a positive correlation between rising social media use and increased rates in teenage depression and suicide. Young adults compare themselves to the seemingly perfect bodies, relationships, and lives of their friends on social media, becoming convinced that they are alone in their suffering.

This sort of depression from comparison often leads to suicide, as does cyberbullying, the amount of readily available information on methods of suicide, and the encouraging and normalization of such behavior on blogs and social sites. The stories of victims lost to the negative effects of social media are tragic and instill a desire to put an end to such heartbreaking events. In certain cases, social media can actually be used to improve mental health, by providing access to educational or health blogs that can promote a better lifestyle or direct them to help needed. The question this issue exposes is that of how society

can possibly put a halt to this trend; though it may be too complex for the judicial system to change anything through law, parents and the rest of society are potentially able to help their children by supporting the uploading of mental health resources onto these platforms they visit so much.

#### WORKS CONSULTED

- Keith Ablow, "Is Social Media Fueling A National Epidemic of Teen Suicide?" *Fox News*, FOX News Network (11 February 2016).
- Jereal Cawis, "New Study Links Heavy Use of Social Media to Depression," *Tech Times RSS* (29 March 2016).
- Kiley Crossland, "The Link Between Social Media and Suicide in Young Women," *WORLD*, World News Group (1 April 2015).
- Katie Bassett, "Exposing the Connection Between Social Media and Teen Suicide," *KVC Health Systems*, KVC Health Systems Inc (September 2014).
- "From the Mag: Penn Runner's Depression Masked on Social Media," *ESPN.com*, ESPN (14 September 2016).
- Carolyn Gregoire "Heavy Social Media Use Linked with Mental Health Issues in Teens," *The Huffington Post*, The Huffington Post (28 July 2015).
- Amanda Hess, "*The New York Times* Claims Social Media Causes Suicide. That's Absurd," *Slate Magazine*, The Slate Group (31 July 2015).
- David D. Luxton, Jennifer D. June, Jonathan M. Fairall, "Social Media and Suicide: A Public Health Perspective," *American Journal of Public Health*, American Public Health Association (May 2012).
- Steve Pokin, "Megan's Story," *Megan Meier Foundation* (13 November 2007). <<http://www.meganmeierfoundation.org/megans-story.html>>
- Gwenn Schurgin O'Keeffe, MD, and Kathleen Clarke-Pearson, MD, "Clinical Report - The Impact of Social Media on Children, Adolescents, and Families," *Pediatrics*, American Academy of Pediatrics (28 March 2011).
- Melinda Ring, "Teen Depression and How Social Media Can Help or Hurt," *CNN*, Cable News Network (5 August 2015).
- "Ryan's Story Presentation," *Ryan's Story Presentation* (16 September 2016). <<http://www.ryanpatrickhalligan.org/>>
- Julie Scelfo, "Suicide on Campus and the Pressure of Perfection," *The New York Times*, The New York Times (01 August 2015).
- "Stat Bite: Leading Causes of Death in the United States, 2010," Office of Statistics and Programming, National Center for Injury Prevention and Control (15 September 2016).
- "The Top Six Unforgettable Cyber Bullying Cases Ever," NoBullying Bullying CyberBullying Resources (23 June 2016).

---

# B EFORE I SLEEP

SHERRY HSIAO

It's midnight and my thoughts are racing.

I close my eyes to see if they'll go away, but all it does is make my head spin faster. I drag my legs onto my chair and give in to the pain that's about to come. With my legs crossed and my body resting on the cushioned embrace of the IKEA chair I assembled myself, I feel a little safer. After spending more than ten hours in the library to keep myself busy, it feels like a waste of my day's effort to let it end like this. But tonight I let it happen.

I squeeze my nose shut with a piece of tissue and let my tears begin to flow. Within seconds, my silent suffering crescendos into intense gasps for air.

Depressive crying is suffocating. I alternate between blowing my nose and taking deep breaths but the light choking comes again and again like waves, weakly but never ceasing.

When I know my eyes have swollen and the skin on my nose begins peeling from all the tissue I've used, I stand up and make my way towards the bathroom. I keep my head down as I'm brushing my teeth. When I finally make eye contact with myself in the mirror, a feeling of emptiness overcomes me.

My naturally downturned lips look especially unattractive tonight. I examine my eyes and know that the layers of my eyelids will be all messed up in the morning. I try to form the smile that I know people compliment, but it doesn't happen and I walk away feeling silly.

Finally, I turn off the lights in my bedroom and wrap myself neatly in the blanket I transported thousands of miles to have with me. I rest the entire weight of my body on my right arm, remembering how he always used to do the same to prevent putting all the pressure on the heart.

After this pathological routine, I muster the last of my strength to hold my hands together up to my face for a wish.

*Dear God, if you really exist, please take away my pain.*

Depression is praying to a god in whom you don't believe.

