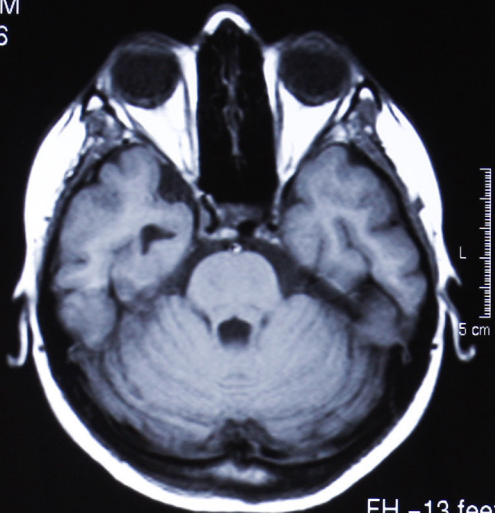


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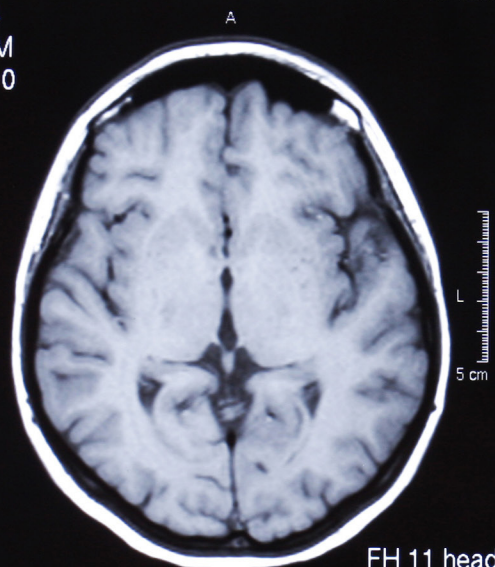
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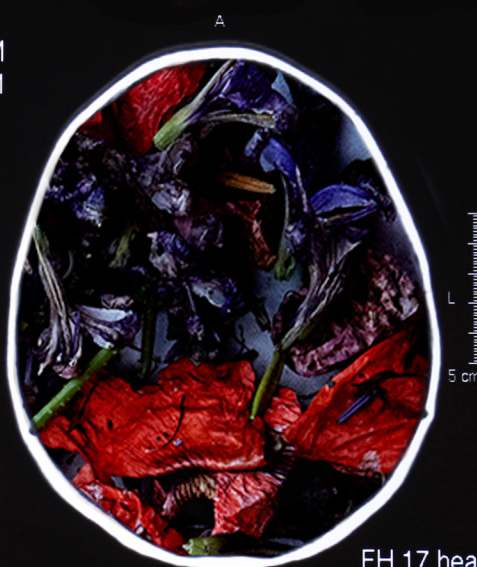
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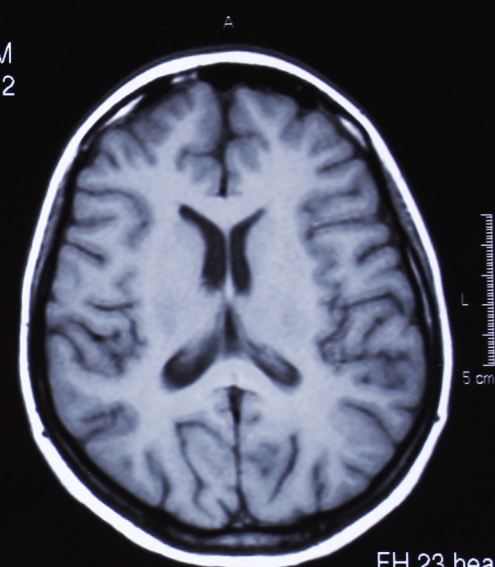
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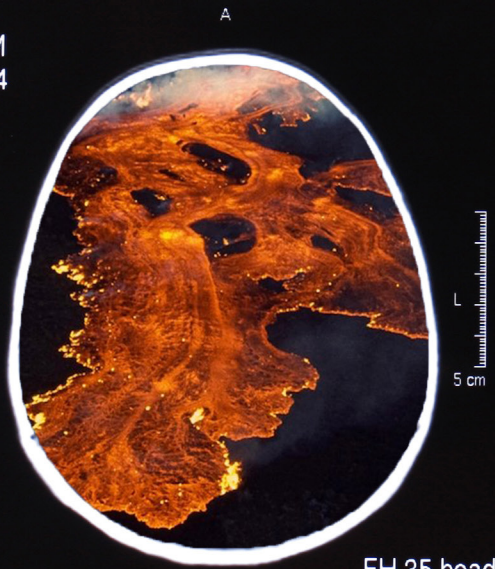
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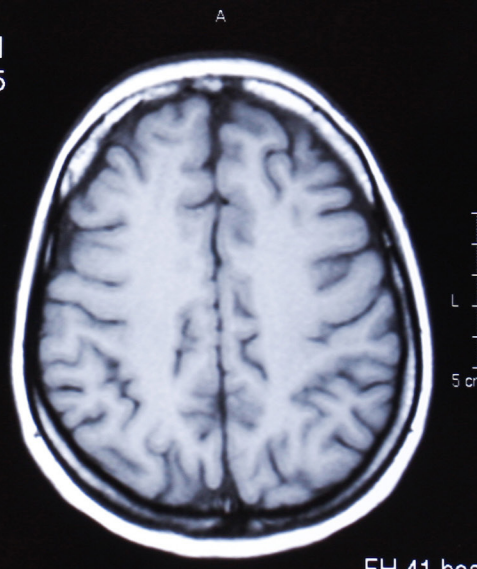
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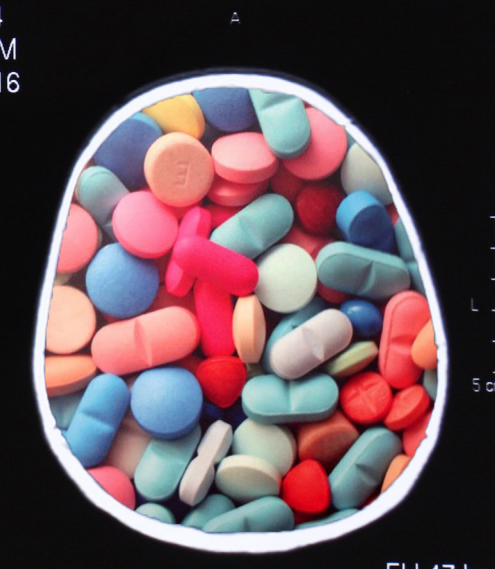
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MISSION STATEMENT

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.

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EDITORS' NOTE

Our time as college students are largely spent observing and constructing our world view in a microcosm of society. Notwithstanding our career paths, medical humanities concepts pervade through all disciplines and lifestyles by reflecting people's experiences with regards to illness, health, health care, and the body. These topics, however, are not commonly discussed for they can be hard to articulate or are too painful to talk about.

Such sensitivity in turn explains the schismatic miscommunication that is present in both national and social conversations. Personal vignettes about these hardships are becoming increasingly commonplace, colorizing the relevant scientific and political discussion in our world today. From a social standpoint, the aspiration to have the ideal college life is often marred by family and personal circumstances, remaining seemingly unacknowledged by the people around us.

Despite the difficulties, several contributing authors brought to light their own stories, thoughts, opinions, and ideas, to share with us how different circumstances could impact one's outlook on life. Many of the featured works are personal, while others derive from observation. The commonality between all of them, however, is each and every contribution constructed poignant scenes of the often hidden, unspoken struggles involved in all walks of life.

Frontlining on the cover of this edition of *The Medical Humanities Journal of Boston College* is "Brain Scan" Samantha Ng. Although mental health is conventionally assessed from a technical perspective, to the average layman, those issues manifest as sources of emotional distress. Hard data and scientific jargon cannot fairly represent the mindset and experiences of not only those afflicted, but also the people closest to them.

"Where it Hurts" by Evelyn Caty describe a young person's battle with chronic pain, and the uncertainty that results

from repeated trial and errors during recovery. People's inability to describe pain results from limited vocabulary that describes the quality and location of it. This isolates the patient from their doctor and can cause them to think their failed communication is preventing their own recovery. Resulting in a severe emotional impact.

Sarah Ramsey's "Three Blind Mice" is a narrative that fragments a conversation, in order to portray how familial relationships can reinforce distorted body images. She examines how negative language surrounding weight teaches children to stigmatize and shame "fatness," and value appearance over health. The piece ends dismally in order to demonstrate how hard it is to overcome eating disorders because they are rooted in the mind and because they require individuals to accept their illnesses.

"Invincible" was created by Michaila Kaufman and incorporates both tangible medical supplies, such as IV tubing, a hospital bracelet, and pins, as well as a sketch. The piece depicts a defiant, powerful woman in the face of her hospitalization. Its optimism demonstrates that patients can still be proud of their bodies and themselves, even when they face atrophy. A person is not defined by bodily limitations, but is shaped by the experiences that come with it.

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,

Derek Xu and Sarah Ramsey
EDITOR-IN-CHIEF AND MANAGING EDITOR

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RESEARCH

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C ELIBACY

KATERINA IVANOV

I am aware of the parts
of my body that have left,
that shrank or faded or died.

Of the follicles and lashes,
the bruises and baby
teeth and the parts
that hold nothing
at all, that just sit
and wait to feel full,

that wait
that wait and wait.

It has been seven months
twenty-six days
eight hours
and fifteen seconds since

I have been touched,
and my body has started to arch
toward strangers without my
permission as if awakened by something
sweet and lingering in the promise
of their mouths and the slip
of skin above their

waistbands.

But I've been trying not
to wince, anymore
when you touch
me. So I slip
under the sheets alone and fill
my mouth with only flannel.

A CREMATION COSTS THREE

MICHAEL QUINN

A cremation costs three
hundred dollars. Each lick
must be a couple cents, slobbering
all over flesh that approaches
rubber that approaches
mud. I fed you to the
mouth when you fell asleep.

THREE BLIND MICE

SARAH RAMSEY

Three women and I are sitting on a porch. Technically, it is four women. I am twenty years old and have moved well beyond the awkwardness of puberty. But I still feel like a girl. One of them starts talking about when she had a parasite and lost fifteen pounds. How the other girls were jealous of how she could eat anything. She tells the story as if she were mocking their absurdity, for choosing a disease over their health, but ends the story with too little fire.

She was proud of that parasite.

Another one jumps in and admits that whenever she drank too much in college and threw up, it was actually a good thing. The “toxins” from the night could all leave her body. Goodbye eight shots of raspberry Rubinoff. Goodbye mozzarella sticks. Goodbye self-worth.

Hello hot stuff.

The third one is nodding her head in agreement and casually remarks how she could lose a few. But when I turn to her, I can see the delicate bones protruding out from under her dress. Her delicate frame has become even more slender since I last saw her.

My stomach is turning inwards; their conversation is making me sick. My body hunches as I curl up in a fetal position. I know their pain, but am angered by it.

I want to put plates of hamburgers, french fries, cake, and pasta in front of them. I want to force them to finish every last morsel. I want to put healthy, pure fat on their bones to protect them from disease, heartache, and insecurity.

I want them to know that they were my role models growing up.

How I revered their skinny, long bodies, when I still had my baby cheeks. How they taught me that their definition of beautiful wasn't to be strong, but to be self-degrading, weak, and sad. How I followed suit, and forced my body to fit in their shadows. How I would weigh myself every thirty minutes. To see if that glass of water had made me fat. How I skipped meals and lied to my loving parents.

But most of all, I want them to see that their method of living can be changed. I changed.

I gave up the act.

I want them to know that they can still be beautiful even if they don't fit into size zero dresses. That their worth is not an encompassment of their appearance.

That they can be powerful.

But I know I can't force others to believe. My sense of truth is distorted when it reflects in their eyes. They will be blind until they choose to see.



SKIN
Sarah Mia Duran

A REFLECTION ON ACCOMPANIMENT IN THE FACE OF SOCIALLY ISOLATED ELDERS

BRIDGID LAWLOR

Little Brothers Friends of the Elderly, my PULSE-elective service placement through Boston College, has allowed me to serve the needs of those in the elderly population who are rendered powerless through the social injustices of being isolated and lonely. I have come to learn that the social injustices affecting this target group can be identified in theological terms as being both a social sin and sin of omission. A social sin can be described as the ideological attitudes that are viewed by a dominant group in society that render other groups powerless and vulnerable to marginalization and are ultimately reinforced in societal structures through the actions of this dominant group. The social sin that I see contributing to the factor of social isolation in the elderly is our culture's blatant neglect for caring for its elders. This is also seen as a sin of omission, in which we as the dominant members in society are omitting to care for the lonely elders that are in need around us.

In his piece in *The New Yorker* titled, "This Old Man," Roger Angell describes how the dominant group in social situations often renders elder members in conversations invisible. He writes about how our conversations are often held in front of elders, but not with them.¹ This describes the phenomena of anomie, in which many elders are surrounded by people, but are deemed invisible and unworthy of our attention. Therefore, the dominant ideology of those 64-years and younger contribute to actions of neglect towards caring for those whom are our elders through sins of omission and social sin. Furthermore, the lack of care and attention is inevitably causing the social isolation that causes elders to have such adverse health outcomes. In an interview that I conducted with Amanda Bilski, a Tufts medical student and a Fellow with Little Brothers Friends of the Elderly, she describes a phenomenon in which the patients that she sees in her geriatric position in a primary care office often consist of elders who are brought to their visits by family members and friends. She concludes that because of these support systems, these elders have both better access to healthcare and stronger health outcomes.² She spoke about social isolation and health outcomes in the elderly as being similar to "the chicken and the egg." Negative health outcomes can lead to social isolation, but social isolation can also lead to negative health outcomes. She told me that there are many elders that don't have the opportunity to see a geriatric physician because there is simply no one there to take them.

When I sat with John Killoran on a park bench outside of his subsidized housing building in Fenway one afternoon, he told me that he needed to see the eye doctor for his blindness, but he couldn't find anyone to walk him to the doctor around the corner. I was faced with witnessing a scenario of an individual living in the heart of one of America's most populated cities, yet not having one person to ask for help. This is a result of our social sin towards the elderly. This is why I became an ally. I am an *ally* to this population because I am not considered a member in this target group, but I have spent the past few

weeks proactively working to alleviate social isolation in a few elders' lives by providing *accompaniment*. Paul Farmer says to accompany someone, "is to go somewhere with him or her, to break bread together, to be present on a journey with a beginning and an end."³ The beginning of our journey—the elders' in Boston in conjunction with my own—was on September 30, 2016, and it will end on December 16, 2016. On our journey, I have visited elders in their homes and in their assisted and subsidized housing placements. Being an *ally* in accompaniment isn't glamorous or easy. Entering into someone's home that cannot physically see the piles of mold or dirt in the corner or the expiration dates in the fridge that leave traces of sour smells is very uncomfortable. Asking elders conversational questions about their family and friends to hear that they have none that are living or that reside in this part of the world is confusing. Asking an elder if he wants to walk outside on a nice day only to hear, "I can't and I don't feel like trying," is awkward. Running to get an elder a gallon of milk and cookies with exactly \$4.40 in my hands is challenging. Hearing that an elder's eye is missing because he was caught in the crossfire of a stone fight in Southie is heart wrenching. But, as an *ally* on this journey and as a member of the youthful, physically-, and mentally-able dominant social group in society, I know that I have certain privileges that allow me to walk *with* the socially isolated elders on their own journeys.

As an ally, I do not go into elders' homes and heal their blindness, fix their attitudes about life, or change their political views and ideals. Instead, as an ally in accompaniment, I enter an elder's home and engage in conversation and bring a sense of care and respect to the elders around me. It appears to be much more simple than it is. I cannot transcend the moments experienced on the journey of accompaniment into proper words. However, these moments look like the tears shed from the elders at the conclusion of my shift, the stories of elders telling me that they called their son to tell him about our visit, and the elder woman from Iran who looked past our religious differences and called me her daughter. Moments like these create a sense of connection between those seen as invisible and myself in the group of youthfulness. It is during these moments of accompaniment that I have found myself considering the fact that I may one day actually be a part of this group.

It is easy to look past elders that have lost their loved ones and have survived to an age past of all of their friends without realizing that this fate is often inevitable for us. My placement has allowed me to question why we ignore a situation that is at the foot of our very own fate. When we walk by an elder on the street corner, shaking and trembling with a cane, *why do we look away?* I believe we look away because it is not easy to recognize that these issues and this fate are inevitable in our very own cycles of life. It is not easy to acknowledge that we may live far away from our parents and our grandparents and don't give them a call as often as we should. It isn't easy to watch a group in our society suffer from the unavoidable factors of aging. However, we are both a part of the problem and the solution of social isolation in the elderly population.

The solution occurs when we become allies through accompaniment and engage the elders in our lives by breaking bread with them and including them in our conversations and our daily interactions of life. We become advocates when we tell our stories of being allies. When I discuss what I witness in the homes of Betty and John, or in the group home at St. Cecilia's, I become an advocate. When I speak for those who I have witnessed being rendered invisible in society, I become an advocate.

When I confront my temperamental inclinations to turn my head and look the other way, I silently show change to those around us.

After walking home from St. Cecilia's in the pouring rain one Friday night, I saw a 94-year-old woman from the home moving inch-by-inch in a wheelchair to travel one block to the store. As I watched her slowly approaching me at the street corner, I realized that it is easy to compartmentalize being an ally at a service placement and to neglect to be an ally in real life. However, I immediately ran over to the elder and guided her wheelchair onto the sidewalk path. When I looked around, I saw that we were in the middle of Fenway in downtown Boston, and people were looking at me as if I were engaging in a highly unusual act. However, by showing the few pedestrians on this street corner the power of loving, caring, and respecting the elderly, I became an advocate.

The journey of my placement may end in December 2016, but I have become an ally and an advocate for this cause for the rest of my life. I have started calling my grandmother with Alzheimer's more frequently, asked an elder professor to have dinner together, and smile and say hello to every elder I see on the street corner. This is a cause that I will not let go of, even when I am an elder myself. I invite you to join me in becoming an ally by spreading kindness to the elders in our society.

ENDNOTE

1. Angell, Roger, "This Old Man," *The New Yorker* (17 February, 2014). <<http://www.newyorker.com/magazine/2014/02/17/old-man-3>>
2. Bilkski, Amanda. Telephone Interview. 28 October 2016.
3. Farmer, Paul, "Transcripts-Accompaniment as Policy," Office of the Secretary-General's Special ADvisor on Community-Based Medicine & Lessons From Haiti. Kennedy School of Government (25 May 2011).

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SARAH ZHUKOVIN

These things do sadden me.
I wrap myself up and I count to three.
I close my eyes once and I can see me,
in a wool sweater and I'm 43.
I'm looking at my children's eyes and they
Believe me to be so wise
But I'm reliving the moments when it wasn't true:
When I'd search for sadness and clutch onto inevitable, painful truths
I would spend too many moments within or without
Blind to what being is about—
floating off and counting to four.
Imagining the future at my door,
The problem being I always did answer
An unforgiving fear growing in me like a cancer
That I'd be too busy counting to five
to ever shake it off and live my life.
But my tremors are surreptitious, unmerited, unclean.
The night is old and I am seventeen.
I do not cry in front of them.
I do not feel much at all.
I know that this is impermanent,
Although my pride stands tall.
The problem is I know my habit's atrocious
I'm too consumed by diagnosis,
Impairing my ability to focus,
I am a stubborn, slow blooming lotus.
Because when I see all of these beautiful faces
I know I'll miss them; I'm a fool

But not so much that I should cry in front of all of you.
What else can I do?

It is frightening to look back at my own skin
I always wonder if it'll be the same the next time I look again.
This is the thing that saddens me:
That change is imminent and from it I'm not free

I lie here and I pray that it does me well.
It's not easy though at the same time it is easy to tell

My fries are wet with tears,
I don't know how to be present,
I don't know how to be here



SKIN

Sarah Mia Duran

THE MOMENT I KNEW

ANDREA CHACON BORGES

He was the kind of man who would suit up for every occasion. Cufflinks neatly polished, leather shoes on point, beard shaved to perfection, hair meticulously combed to the side, and just the right amount of cologne. He was the kind of man who would always be the first ready for every occasion... But now, things were different. We all sat down at the dinner table, waiting. The only movement came from our eyes, as they searched for a place on the wall or floor to lock themselves onto. They were searching for anything but the eyes of the others because, in them, we would have to face the truth. In them, we would have to confront what scared us the most.

“Happy Father’s Day!” exclaimed one of my cousins, as my mom and aunt slowly brought my grandfather into the dining room, one on either side of him. Instantly, everyone started engaging in mindless chatter to mask the fear and despair that hung in the atmosphere. I was the only one who remained silent, stunned. It was the first time I ever saw my grandfather in his pajamas-- other than when it was bedtime. Slimmer than yesterday, pronounced bags under his blue eyes, ruffled hair, beard scruffy and unattended. That single sight hit me like a thousand needles piercing into my body. The reality and severity of my grandfather’s cancer always lurked around the corners, silently weighing on me. However, this time it came without shame and punched me right in the stomach. My grandfather was still my grandfather, yet his disease had somehow changed him; it was slowly stripping him of his characteristic vitality, dissolving any need or desire to polish himself and to wear the suit and tie he probably would have worn for dinner that night. Holding back tears, my heart started racing and my eyes desperately searched for a place to take refuge when, suddenly, I realized that my grandfather’s eyes were doing the same. Taking a deep, deep breath, I finally decided to lock my eyes onto his. It hurt. So much. It was devastating understanding everything that single look entailed, but at least it made us feel together in our fear, our grief, our heartbreak. It made us feel together in our hope, as if we were one facing everything that was to come.

A TLAS

ANDREW DAVIS

Pardon the interruption- I have something to say
I'd like to put in words how I felt the other day
20 pounds of textbooks, notebooks, a Mac
But that's not all that I carried upon my back.

I move through these halls, sidewalks, and days
How I dress, how I walk, in attempt to look cool
But looking around in this hurried haze,
Am I a human or a fish, swimming round this school?

The need to stand out, to be something more
Both drives me on! and drags me down.
Because as time goes on, I become more sure
That never! Will I be sheriff, of my emotional town

Oh, pressure creates diamonds?
Well it cracks a lot of eggs.
And it weighs me down far more
Then my body upon my legs.

The solution, some say, is psychiatric help
And for some, I'm sure this is true
But something so drastic? I haven't cried in a week!
I go regardless. It's the bold thing to do

So I meander into her office
For my first time, hopefully not hers.
"Judy? How do you do!"

I carelessly say, through thunderous nerves

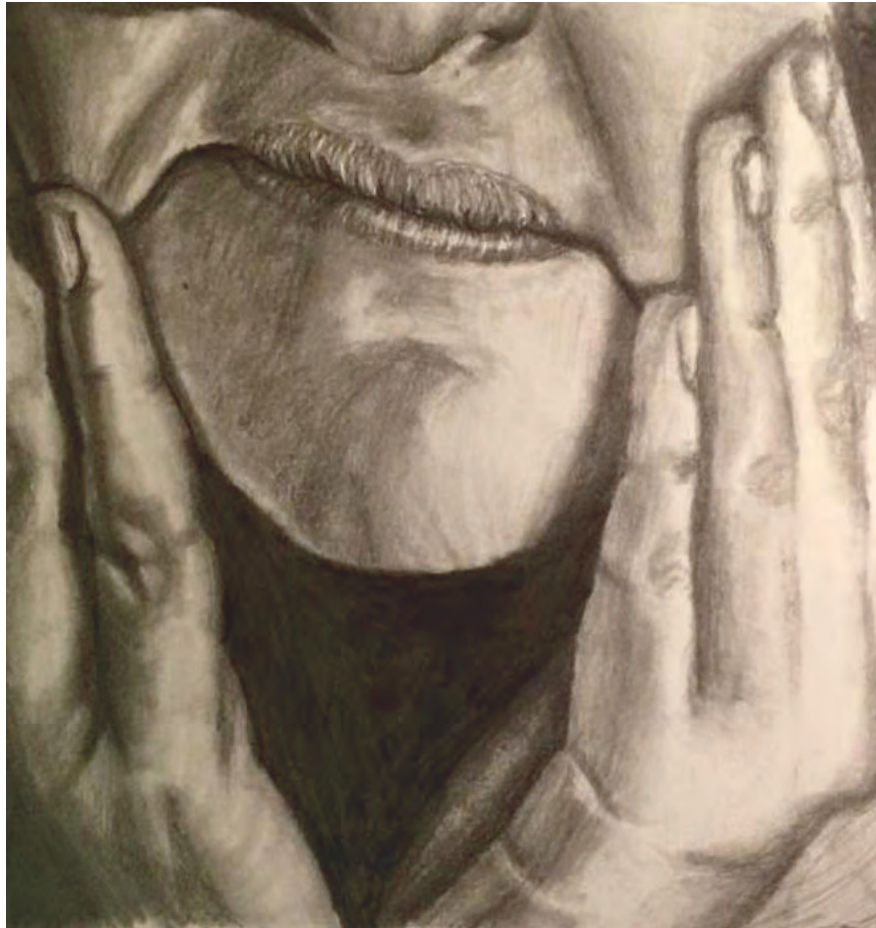
The plaque on her desk
To remind me of her MD
But by now I've begun to think
It'll take more than a degree in psychiatry

To understand this. Where I went wrong.

When the record fell off. My head's absent of song.

Am I a train off the tracks?
A puzzle missing a piece?
Is it my fault, is it yours?
I don't know. I don't know. And I probably won't, not anytime soon.

I think those days are behind me.
Or could just be taking a break.
But onwards I move. Another smile to be faked



SKIN
Sarah Mia Duran

ABSOLUTE AUTONOMY AND PATERNALISM IN MEDICINE

GUY GUENTHNER

Art, to me, has an expressive dichotomy between the individual artist and the collective audience. Whether listening to a piece of music, watching a ballet, or pondering a painting, I find myself reflecting on the connection between the individual artist and the collective of people who will witness and enjoy the work. Even within the art itself, there may be a single person of focus or a large variety of individuals. I began to notice that in any single room there could be a portrait of a wealthy aristocrat on one wall and directly next to it a scene of peasants drinking in a tavern. As I wandered the halls of the MFA, I found myself noticing these variations within works all around me.

As I tried to focus my vision through the perspective of Law, Medicine, and Ethics, I realized the practice of medicine, much like art, involves the frequent interplay between the individual's experience of independent choice and the collective thought or wisdom, expressed through a physician's practice of medicine. Further, I began to think about how this relationship was epitomized by the contrasting ideas of patient autonomy and physician paternalism. I ultimately chose *Lake Nemi* by George Inness and *Museum Epiphany III* by Warren Proserpi as my two works to investigate based on their portrayal of autonomy and paternalism and the suggestions they make about the necessity of balancing both concepts.

Patient autonomy has taken an unprecedented position as

one of the most valued aspects of modern medicine. The importance of patient autonomy, however, has only developed quite recently and has been in no way a historical mainstay of medicine. Many believe this apparent rise of patient autonomy has occurred in response to overpowering paternalism. In the words of Richard McCormick, "the last 30 years have seen a gradual rejection of paternalism ... the attitude and practice that visits a benefit on a patient or wards off a harm without the patient's knowledge or against the patient's preferences."¹ Perhaps the first open rejection of physician paternalism, however, occurred in the case of *Schloendorff v. Society of New York Hospital* over one hundred years ago. In 1914, a physician removed a tumor from a woman's leg without her authorization. The woman developed gangrene as a result of the procedure and sued the hospital over the physician's actions. The court decided the doctor was not only negligent, but also trespassed on the woman. The court documents included one of the earliest definitions of patient autonomy by stating, "every human being of adult years and sound mind has a right to determine what shall be done with his body."² This case represented a paradigm shift moment in which people began to see the dangers of paternalism and the value in respecting patient's desires.

The focus on patient autonomy intensified in the years following the *Schloendorff* case. In response to increasing medical research during the mid-20th century, the National Commission for the Protection of Human Subjects crafted The

Belmont Report to establish ethical guidelines for medical researchers. The protocol's provisions for respecting patient safety and privacy in research studies were founded on Immanuel Kant's philosophy to "act so that you treat humanity whether in your own person or in that of another, always as an end and never as means only."³ Ultimately, the *Belmont Report's* interpretation of Kant's instructions on the respect for persons became the respect for autonomy described as "refraining from obstructing the actions (of autonomous persons) unless they are clearly detrimental to others."⁴ This concept of patient autonomy was promptly applied not just to medical research, but clinical practice as well.

In Western medicine today, patient autonomy has become what many consider to be an absolute right. Individuals who believe in absolute patient autonomy are represented by John Stuart Mills' famous quote "Over himself, over his body and mind, the individual is sovereign."⁵ This "absolutization of autonomy"⁶ has resulted in the almost total rejection of physician paternalism and many patients now feel there are only select circumstances in which a physician may impose his or her will over a patient. These circumstances align with the principles of the *Belmont Report* and are summarized again by Mills as he explains "the only purpose for which power can be exercised over a member of a civilized community, against his will, is to prevent harm to others."⁷ By providing such limited opportunities for a physician to act on a patient, the door for any sort of "doctor knows best" paternalism has been closed. Physicians, for all intents and purposes, function as only a medical advisor or counselor if absolute patient autonomy is preserved.⁸ Such circumstances, however, places the executive decisions in their hands – a power that is often conflated with emotional distress in the face of uncertainty.

When I encountered *Lake Nemi* by George Inness, I was struck immediately by the sense of absolute autonomy portrayed and the parallels that could be drawn between the scene and medicine. The subject in the painting is a man walking along a barely visible path. He is completely alone and seems small compared to the massive landscape around him. He is following a path that disappears over the crest of a hill directly in front of him, leading the viewer to wonder where the path leads and whether the traveler even knows where he is headed. I began to imagine this lone traveler to be analogous to an autonomous patient on a journey through the immense world of medicine. The vastness of medicine may at times make the patient seem comparably quite small, just as the man appears in the painting. Further, like the traveler, patients often are following medical paths without knowing where the path will lead or where they will ultimately arrive. Finally, like a patient who desires to be fully autonomous, the traveler is free to make decisions about his journey. At any point, he could deviate from the path or stop altogether. As I continued to create these parallels in my head and consider the value of autonomy, I made a realization: what if the man was actually lost? I began to consider the drawbacks of his complete autonomy and his potential interest in guidance on his journey.

Despite the acknowledged importance of respecting patients' desires, some wariness has arisen toward the implications of absolute autonomy, as suggested by the possibly lost *Lake Nemi* traveler. At the extreme end, Pope Pius XII counters Mills' claim and questions the very possibility of absolute autonomy by claiming the patient "is not absolute master of himself. He cannot, therefore, freely dispose of himself as he pleases."⁹ Although this claim may be too steep, there are other valid claims to the adverse effects of absolute autonomy. The first of these effects is the negative

impact on the patient-physician relationship. Albert Jonsen expresses his belief that respect for autonomy has “retarded and undermined the re-establishment of the patient-physician relationship.”¹⁰ He continues to say that although the respect for autonomy clearly has priority as an ethical principle in medical research, as suggested by the *Belmont Report*, this may not be the case for clinical ethics. This claim is based on the premise that the purpose of clinical medicine is to cure and aid the immediate patient, while medical research seeks to benefit future patients, not the directly involved study participant.

Absolute autonomy also places an immense burden on the patient. Once patients have decided that they will be in sole control of their medical decisions, they have taken on the weight of comprehending their illness, including the diagnosis, prognosis, and direction of treatment. Dostoevsky understood this perfectly well when he wrote, from the perspective of the Grand Inquisitor, “there is nothing more alluring in man than his freedom of conscience, but there is nothing more tormenting either.”¹¹ By allowing patients to assume total control of their medical decisions, society has inadvertently placed burden of choice on individuals who are already very likely overwhelmed.

Finally, absolute patient autonomy has unforeseen ethical implications. Richard McCormick worries that when “the rightness or wrongness of a choice is reduced to a signal factor that it is this individual’s choice, morality has been impoverished.”¹² This highlights the necessity of continuing to question not only who is making the medical decision, but also the ethical elements of the choice itself. We cannot allow ourselves to become so wrapped up in the rights of the patient to lose sight of the fact that decisions can in fact be considered good or bad, better or worse, right or wrong. At

times, it seems as though “absolutizing autonomy”¹³ provides physicians with an escape from tackling the actual ethical or moral aspects of a decision.

In light of the limiting aspects of absolute autonomy, there seems to be a realistic opportunity for “the right kind of paternalism.”¹⁴ The question then becomes what is the “right kind of paternalism” and how do physicians avoid the same professional attitudes that led to an over-zealous turn towards absolute autonomy. There is no doubt that many patients see the physician as the gatekeeper to a world of knowledge or practices that can only be accessed through the benevolence of the gatekeeper.¹⁵ With this in mind, it is important to recognize the position a patient may be in when they find themselves in front of a physician. Illness has the ability to demoralize patients, change their perspectives, and even cloud their better judgment. Peter Marzuk acknowledges this reality by explaining, “We must be careful not to discard all vestiges of paternalism, particularly those that serve to guard against patient decisions that are ill-conceived because of emotional reactions to illness.”¹² The key foundation for “the right kind of paternalism” may actually be trying first to understand the patient before directing them this way or that.

Once a physician acknowledges the intense situation in which a patient may view him-or-herself in, the physician can begin to practice a form of appropriate paternalism. This renewed paternalism is based on communication and understanding between the patient and the physician. Instead of the adversarial roles created by absolute autonomy, the patient and doctor can form an alliance that is focused on arriving at a reasoned decision with which both parties are comfortable. The physician should explain the diagnosis, prognosis, describe pros and cons to each treatment op-

tion and then, instead of asking the patient to make a choice, the physician should recommend a course of action.¹³ If this process is followed, physicians will be able to feel they have done their job while patients can feel as though they made the ultimate decision about their treatment.

Having considered autonomy and its limits, as exhibited by the traveler in *Lake Nemi*, I turned and found myself looking at *Museum Epiphany III* on the opposite wall. The painting focuses on a mother and her child in an art museum, the child peering up at a white marble sculpture. Her facial expression is one of curiosity, but also exhibits a degree of confusion. The mother is bent over and turned toward her child as if she is explaining the piece in front of them. In the background, there are other museum patrons, noticeably all adult, investigating various pieces of art. Like *Lake Nemi*, I began to draw parallels between *Museum Epiphany III* and the medical world. I imagined this-little-girl-surrounded-by-art as a patient enveloped by physicians in the foreign world of medicine. However, unlike the traveler in *Lake Nemi*, another person stands alongside this little girl. The mother could represent a physician accompanying a patient through the complicated aspects of his or her medical journey. The girl is free to make her own decisions about the art, but her mother is there, aware of the girl's confusion, to provide counsel and guidance. The scene in *Museum Epiphany III* began to represent what I felt Marzuk described as "the right kind of paternalism" or "maternalism" for this particular work. I must admit I stifled a laugh when I looked at the descriptive plate next to the piece and saw *Museum Epiphany III* was painted in collaboration between the artist and his wife.

The recent past and present of medicine seem to exhibit a constant ebb and flow between overpowering paternalism

and absolute patient autonomy. It is important to look at the patient, like the traveler in *Lake Nemi*, as an individual on a journey through immense, unfamiliar territory. They must feel capable of making decisions according to their own desires and a physician needs do his or her best to understand both the patient's perspective and decisions. However, it is unwise to dismiss the knowledge and guidance a physician can give to his or her patients, just as the mother gives her child in *Museum Epiphany III*. Perhaps, just as I stood in the middle of the gallery, midway between the two paintings, we must see the positives in both aspects of the patient-physician relationship and conclude that the truth of the matter is not absolute.

ENDNOTES

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Lake Nemi
George Inness, 1872



Museum Epiphany III
Warren Proserpi, 2012
Courtesy of the MFA

SHE'S MY LITTLE COUSIN

SARAH RAMSEY

I don't remember when she was born,
But I remember when she was small enough,
To toddle around in a little puffy dress,
With Mary Jane shoes,
And a cute little pixie cut.

She's my little cousin.

I knew her parents' divorce was tricky,
But I didn't know how emotionally difficult it was on her,
When she hid behind couches,
Taking solace in cookies,
Hugging her knees tight,
To escape the sound of banging doors.

She's my little cousin.

I knew she was more overweight than I was as a kid,
I didn't know that she knew,
And that she felt guilt, shame, and ugly because of it.

She's my little cousin.

I had my own issues,
Starving and lying,
I took solace in control,
Hugging my knees tight,
To escape the sound of my own negative voices
She didn't know.

She's my little cousin.

I finally told her,
How I used to strive for emptiness,
To weigh nothing,
To feel nothing,
But this didn't solve anything.

She finally told me,
How she used to strive for fullness,
To eat something,
To feel nothing,
But this didn't solve anything.

She's my little cousin.

I told her,
One day,
You will be able to feel full,
Not because of the cookies you ate behind the couch,
Not because of the glasses of water I used to chug,
But because you will look at yourself in the mirror,
And see the beautiful, strong, smart girl that I see.

One day,
You will be able to feel something,
Because you decide you are done,
You will let go of your knees,
And get out from behind the couch.

It takes time,
It took me a while to realize that.

The doors will always bang,
The cookies will always be there,
But they don't solve anything.

She's my little cousin.



I NVINCIBLE

Michaila Kaufman

WHERE IT HURTS

EVELYN CATY

The day I learned that I needed hip surgery, I cried tears of relief.

On September 23, 2013, I was playing in a JV field hockey game when all of a sudden, after passing the ball to a teammate, I felt something go wrong. It was... a pop?... a snap?... a tear?... and it came from somewhere in my left backside. I could not identify precisely where—in my lower back, upper hip, or glute—I felt it. As I crawled off the field, I struggled to assemble an explanation to provide the athletic trainer. To this day, I cannot say exactly where it was or what it felt like, but I do know, as the past three and a half years have proven, that something was not right.

For the first eleven months after my injury I was diagnosed with a torn muscle in my hip, but physical therapy did little to relieve my pain. I began to see an orthopedic surgeon specializing in hips, who saw nothing notable on my MRIs and encouraged me to continue treating with physical therapy. After months and months of hard work without relief from the pain, I started to worry that I was somehow *doing* it wrong. Finally, a new MRI of my hip, this time done with contrast dye, showed torn cartilage in the joint. This would require surgery to repair. When, after a year of persistent and unidentifiable pain, as well as numerous consultations with hip specialists, a surgeon walked into my examination room and claimed that he knew exactly how to cure my pain, I sat on the table in front of him and sobbed. The recovery would be long and painful, but at least it would mean I was healing. At this point I would have done anything.

After my surgery, I completed nine months of physical therapy to rehabilitate my hip and the rest of my body. But as the physical therapy came to an end, I noticed that something still felt *off*. I occasionally had that same original pain; it was a pain distinctly different from the normal soreness of post-operative recovery, and I was all too familiar with how it felt. Worried that the operation had failed, I tried to ignore my discomfort for a year and a half. I was terrified that if the surgery had not provided a cure, then nothing could. This past December, after the pain suddenly grew much worse, I finally decided that I could no longer ignore my fears. I scheduled a follow-up appointment with my hip surgeon, who referred me to a spine center to look for other possible causes for my pain. To this day, my doctors and I are still searching for its source.

My pain taunts me. It comes and goes. It moves from place to place. It floats, it hovers, over my mind and body, cruelly defying articulation. The English language offers a myriad of terms to describe pain: sharp, dull, burning, throbbing, sore,

stiff, tender... the list goes on. And yet, my three-and-a-half-year search for the words to most accurately capture my experience has left me with the following clumsy explanation: most of the time it does not feel quite like a throb, but more like a series of discrete pinching and tugging sensations with each movement of my lower body, located somewhere between my sacroiliac joint and L5 disc; other times—when I sit or stand for too long—it aches across most of my lower back. Sometimes, though, the pain deviates from both of these descriptions.

Without looking at a calendar or an MRI report, I can list off the top of my head everything I have done in the past three and a half years to try to relieve this pain—five MRIs, a CT scan, countless X-rays, six specialists, two chiropractors, two injections, and one unsuccessful surgery—including the dates on which most of them took place. But, despite my three and a half years of familiarity with this injury, I cannot explain how it physically feels.

Three years ago, I spent my time training for the sport I loved, pushing through the pain of conditioning and doing everything I could to prevent the pain of injury. Now, I spend my time catering to physical pain, altering my movements and avoiding certain motions altogether. I prepare for each doctor's appointment by obsessively practicing my story—the words I've carefully picked to best convey how the pain feels—in my head. I brace myself for the disappointment of watching yet another medical professional fumble for a diagnosis. And I desperately hope for the opposite: I hope that one of these appointments will lead to definitive answers. I hope to one day again cry tears of relief like those I cried the day I believed in the miraculous powers of hip surgery.

CLEAN UP ON AISLE TWELVE

SARAH RAMSEY

I am not ok.

Walking through the grocery store,
I am paralyzed with fear,
Waiting to see who pops up around the corner.

I can already hear the conversation in my head.

Hey Julie! Oh my gosh, you look AMAZING!
I am so proud of you,
How do you stay so positive?
You are such a fighter,

You

Inspire

Me.

My stomach curls inward as I see a blonde bob in the distance,
Belonging to a woman whose son used to be friends with my son,
Until my son was dubbed, not “cool” enough.

She sees me, and rushes over,
Almost hitting an old lady in the process.

Oh my gosh, Julie!
How are you? It has been too long!
You look so great!
We should catch up some time!

Let me know if you ever need me to take Tommy off of your hands.
Billy has missed playing with him!

She quickly glances at her watch,
So she doesn't have to wait for a response,
Or wait to hear what I really want to say.

As she retreats,
Her hair swishes over her shoulders,
And starts to turn into Medusa's terrifying locks,
Heads with huge eyes form on the base of each luxurious golden strand,
Taunting me because they know the truth.

I am not ok.

I do not look good, I have lost thirty pounds due to the countless hours I have spent at chemotherapy, throwing up, stressing about what is going to happen, to my family, my son, my husband, my mom who has Alzheimer's and only has me to look after her.

My hair is falling out, but not all at once. So it mocks me. I have too much of it left to justify buying a wig, but too little of it left so people know **something is wrong with me**.

You should not be proud of me.

Do you know the amount of times I have yelled at my husband, cursed God, acted like a baby, started crying in front of my son, and screamed at the top of my lungs?

I am not positive.

I feel hopeless, sad, and distraught with fear and worry. I am not a bloody happy go lucky person.

I am pissed.

I am not a fighter, cancer is fighting me.

I am not your hero.

I am pathetic, weak, and angry.

When I die, I don't want my obituary to say I went down fighting.

That is bullshit.

I went down
starving,
crying so hard that snot was running from my nose,
laughing when my husband shaved his head for me,
asking God WHY I deserved to be punished,
feeling like shit when people glorified my fight.

If it is so inspiring, why don't you do this?

Want me to ask God if I can hand the baton to you?

I am not ok.

T EARING MY MENISCUS AND ALL THAT JAZZ

LISA KURT

When people would ask how it happened, I would rack my brain to think of a heroic scenario, or really just any normal, justifiable explanation. Anything was less embarrassing than the disappointing and sickly ironic truth of it all: I tore my meniscus while “standing up incorrectly” to the song “All That Jazz” in my high school P.E. dance class. (Feel free to pause and listen to that song and soak in the second-hand embarrassment). Just like clockwork, on the third repetition of “all that jazz,” I extended my leg to stand and my knee crumpled, giving off a sharp crackle sound. The teacher noticed a problem when the other dancers began trampling over my frozen, shocked body. I cannot remember the pain, I just remember being overwhelmingly uncomfortable, and for good reason.

The teacher called a golf-cart to take me to the health office, and I sat in the front seat clutching my knee and grimacing, clothed in my obnoxious “I LOVE P.E. DANCE” t-shirt. Upon my glorified arrival, the nurses tried their best to relieve my discomfort. They tethered my knee to scraps of metal and wood, securing it with multiple gauze wraps; my discomfort quickly transformed into a pulsating, searing pain. Not wanting to be ungrateful for their dedication and resources, I smiled at them and asked politely to call my Dad. Feeling like I was overreacting, and honestly in disbelief that I could have severely hurt myself by essentially standing up, I refused to go to any sort of emergency room and settled with a visit to the pediatrician. In hindsight, by shielding my ego with denial, I won myself a whopping ten more weeks with crutches. *Score!*

As predicted, the pediatrician gave me a lollipop and crutches and told me to “feel better.” As you can probably guess, I did not. Another visit and lollipop later, the pediatrician referred me to the local orthopedic doctor. Five weeks had passed since this embarrassment of an incident, and I was ready to legitimize my discomfort. The doctor asked me many questions about what I had heard when it happened: was it a crack, pop, snap, or rip? He made it feel like the weight of my diagnosis was on my ability to remember this trivial fact: *was it a pop or a snap?! It was a snap. But wait I think it ripped!* I settled with “crack”. He told me that “cracks” sometimes happen after “standing up incorrectly.” *Cue: Sigh of Relief.* He ordered me an MRI, and two weeks later, I was back in his office. Finally, in his crisp golden manila envelope, my diagnosis awaited.

His careful doctor hands slid the x-rays out of the folder and he posted them on the light-up board that projected my radiating tibia and femur. Waving his hand over the white, blurry mass in the middle that seemed to have all the answers,

he concluded that I had one of the most severe tears: a bucket handle meniscal tear. My head tilted to my shoulder, my eyes squinted, and my hands nervously fidgeted by my sides; the doctor decided a metaphor would help his case. He explained to me how my meniscus was like a pancake. *Finally, something simple enough for me to understand?! My pancake-meniscus had torn in half and done a full pancake-flip onto the other side of my bone. Where does this poor guy get ripped pancakes? Still, I appreciated the relatable(?) visual.* My confusion was consumed by relief. I trusted him to use his fancy knives and needles to fix me up, and I was thankful that he justified my pain and discomfort with a diagnosis. It wasn't even solely for the sake of my knee or my mind anymore, my arms were bearing most of the burden of this injury. Although firm arm muscles were emerging from the flabs of my arms, my bruised armpits had suffered enough.

Two weeks later, I was rolled into surgery, and passed on to physical therapy (don't get me started on Doctor Olga's "rehabilitating" shock therapy). Overall, it was a collage of uncomfortable and dysfunctional situations that I learned to laugh at. Since it is no fun being injured, I learned I might as well make fun of the inconveniences and ironies along the way. I firmly believe that crutches build character (and muscles) and I reason that laughter is the best medicine. I drove away from my last physical therapy, windows down, blasting "All That Jazz".



SKIN
Sarah Mia Duran