

*The International Journal of*

# WHOLE PERSON CARE

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This special issue of the journal focuses on personal transformation in relation to work in the field of healthcare. A collection of first-person narratives and commentaries provides different insights into how personal and professional identities can be formed and reformed over the trajectory of a career.

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## EDITORIAL

# THE BITTERSWEET PURSUIT OF TRANSFORMATION

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**KEYWORDS:** Transformation, Longing, Transformative experience

**A**s far back as I can remember, I've had a deep longing for transformation. Growing up, I always felt too poor, too religious, and too odd to fit in. And I desperately wanted to fit in. Over time, this evolved into wanting a clear sense of purpose. I remember as a physical therapy student, longing for some sort of life-changing catastrophe. *If only I had a spinal injury*, I thought, *then surely fulfilling the minutia of daily life would become a worthy, heroic undertaking*. As of late, the focal point of my longing has rested upon my relationship with fear. I am so tired of being afraid. Afraid of failing, afraid of how others think of me, afraid of wasting my potential.

Despite this perpetual longing, I'm slowly realizing that I have no idea *how* I change. The processes underlying transformation remain a mystery to me. The archetypes from my Christian upbringing reinforce this mystery. Resurrection, conversion, salvation – these transformations seem to involve a type of magic that leaves me blind to their mechanisms. I'm also starting to realize that they have distorted my view of transformation, which has focused on the need for a singular, life-defining change.

One of my favorite movies focuses on this type of transformation. *Adaptation* is a pseudo-autobiographical film that sets up the screenwriter's fractured selves as identical twin brothers.[1] One, an artistic genius that is socially awkward and crippled by self-doubt. The other, an affable buffoon that is confident and charismatic, but constantly underachieving. The film culminates with a surreal scene that transforms these

two broken personas into a cohesive whole – one enlightened brother emerges, having integrated his twin’s virtues, while shedding their collective vices. I love this picture of transformation. It fuels my perpetual longing for change. *If only I could stop being afraid – I would finally become the person I was always meant to be.*

And, yet, clinging to this romanticized image, seems to blind me to the important change that I have experienced. My life changes pale in comparison to these dramatic prototypes. However, in my quieter moments, I see that, slowly – and in a decidedly non-linear way – there has been an arc of transformation in my life. Striving, stumbling, winning, loosing, slowly becoming. The trajectory of my career provides, perhaps, the most explicit testament to this change. After training and practicing as a physical therapist, I switched fields to earn a PhD in experimental psychology. I was keen to explore mind-body connections in the context of chronic pain rehabilitation. Since first joining faculty as a university professor eight years ago, I’ve slowly reoriented my research, focusing on new themes of suffering and selfhood. My work today only tangentially interfaces with where my career started some twenty years ago. Looking back, each step in this trajectory seems to have helped me understand and cultivate my idiosyncratic passions and gifts; allowing me to slowly re-orient my work to these inner bearings.

Navigating these vocational changes, however, has been a murky and fraught process – I have difficulty pinpointing any particularly transformative events and agonized over each minor decision. I think part of my longing for grand, life-altering, change, is wanting an experience so dramatic that it will be obvious that a transformation has occurred. I want to see it. I want others to see it. I don’t want there to be any doubt.

Longing for this type of grand transformation also seems to shield me from the inherent messiness of mindfully living through change. I put a lot of value in cultivating joy and happiness in my daily life. A constantly evolving daily practice aims to help me feel centered, mindful and present. At face value, longing for transformation is fundamentally incongruous with a deep sense of peace and acceptance in the present moment. Thinking of transformation as a singular, magical event helps protect my inner equanimity from the things about myself that I’m just not ready to accept. It’s as if my vision for change is that one day, I’m a peaceful Zen master, and then – *Poof!* – the next day, I’m a totally different, peaceful Zen master. Transformation complete.

In recent months, I’ve started to cultivate a new vision. Susan Cain’s book, *Bittersweet* has helped me with this process.[2] The book beautifully captures the intermixing of joy and sorrow that often characterize experiences of longing. It helped me recognize and embrace the incongruity of finding peace and joy in the present moment, while simultaneously wanting something else. It’s also helped me find more evidence of change in my everyday life.

And, so, I'm choosing to see my new leadership role with this journal as a type of transformation. I see this journal as an important vehicle for bridging the inner and professional lives of healthcare researchers, educators, and clinicians. But bridging this gulf in my own life is still quite new to me – I can count on one hand my published manuscripts that use the first-person. Working on this issue (my first as Editor) has been such an educational, rewarding and – as I'm slowly starting to see – transformative experience for me. Each of the contributions illustrates, in such different ways, what transformation in healthcare can look like. They have helped me cultivate new insights into my own personal and professional changes. My hope is that they will similarly inspire you – prompting new ways of understanding and aligning your ever-evolving inner and professional worlds. ■

## REFERENCES

1. Jonze S. *Adaptation* [film]. United States: Columbia Pictures; 2002.
2. Cain S. *Bittersweet: How sorrow and longing make us whole*. United States: Crown Publishing Group; 2022.

## Biographical note

Timothy Wideman is a physical therapist and associate professor at McGill University. His research aims to help clinicians better understand and address suffering associated with pain, and to improve how future health professionals are trained to care for people living with pain. He started serving as Editor-in-Chief at the beginning of 2023.

## THE FOLLOW-UP VISIT

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**KEYWORDS:** Communication in healthcare, Patient coping, Terminal illness, Caregiving experiences, Doctor-patient relationship

I had a dream in which I am standing next to my husband's doctor in a crowded elevator. He is so tall, his face looming so far above my head that I cannot see it when I turn to say hello. All I see is a beltful of papers and reams of papers and medical instruments spilling from his white coat. This despite me knowing he is barely taller than I – same height when I wear heels. Feeling somewhat inappropriate to speak to his pockets, I say nothing, and he exits.

I know he has a terminal illness. I have had patients with the same diagnosis. I have held family meetings to explain the symptoms and treatments and poor prognosis; to advise on long term and palliative care. Now I am on the receiving end of such discussions but feel like I know nothing. I know the natural course of the disease, yet each day seems to raise new issues. I am frustrated he is so resistant to complying with standard treatment while he keeps asking about experimental ones. I sometimes do not understand how my husband, a fellow physician, could have so little insight into his own health and abilities. Does the doctor realize that in the whole year since diagnosed, he has not read even a single paper on the illness?

Maybe it is better not to know. He is 39 and will die before his parents. I am 30 and will be a young widow. He most likely will die from aspiration pneumonia. Or maybe one day he will have such a bad fall that something critical will get broken or contused or whatever lands people in the ER for a lengthy, complicated hospitalization that seems to be the last days of so many of our patients now. I know this. He is afraid he will not be able to breathe. We talk of making wills and mandates on our first wedding anniversary.

I have learned about the significance of the follow-up visit. It has been marked on our calendar for months and my workweek – no, month - planned around it. He takes great pains to wear his newest shirt and be meticulously shaved. We arrive 20 minutes early. He totters into the examination room, proud to show he still can walk; oblivious to the fearful cringing faces and darting hands ready to catch him in a blink. We recount a litany of changes since the last visit – all for the worse. Medication suggestions are made. “Anything else to report?” Because there is a meeting, a sick patient on the ward, it is the end of the day. “No, that’s about it.” We leave. We already have overstayed our welcome.

Wait! I want to tell you how my husband is a shell of his former self. He ran marathons and played tennis; he taught me how to ski. He survived graduate studies and medical school and was in a grueling residency program before quitting as strange symptoms we would not see robbed him of speed and dexterity and speech and competitiveness. He is witty and loving though his cognition is slowing. I pick him up after yet another fall and change his diapers; he picks up my spirits and changes my perspective on life. “Anything else to report?” “We are losing hope. Can you help us?”

But I guess these are not relevant to say. I feel inappropriate speaking to his pockets. ■

## **Biographical note**

Wendy Chiu is a geriatrician at the McGill University Health Centre, and was her late husband’s primary caregiver for over a decade until he died in 2013 from complications of multiple system atrophy. She tries to use the experience to better care and advocate for her patients and their families, and hopes they feel understood.

## AN ANNEALING

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**KEYWORDS:** Empathy, Connection, Presence, Death

**W**e met in a frigid Connecticut conference room during a late March Nor'easter. The obliterative storm had delayed our flights and made mockery of the lightweight clothing we had each packed. We thought it was Spring. Tiffany was a regular on the speaking circuit and had been invited by the state's hospital association to deliver a talk on the lessons of her second double lung transplant, as a patient advocate. I was presenting on my own critical illness and recovery, as a critical care physician. My invitation was based on an essay I had recently published in the *New England Journal of Medicine*, and public speaking was new to me.

She recounted having spent her childhood in a body ravaged by cystic fibrosis, tethered to breathing treatments, hospital beds and complicated antibiotic regimens. The first pair of donor lungs she had received offered a tentative way forward. When her body quickly and violently rejected the new organs, she believed she would die. She somehow found a way to settle into the cataclysm of her body, without resentment or regret, and said her goodbyes, only to be unexpectedly granted a second pair of donor lungs. It was disruptive, she said, finding herself alive again, having prepared herself to die. She may have even used the word annoyed. The audience loved her.

Hers was a visceral, bodily kind of knowing. She was so attuned to her internal landscape, she could tell if her immunosuppression levels were off by how irritable she was when she was hungry, or how poorly she slept. In this way, she embodied the kind of intangible knowing I'd been trained to devalue. She was practical and oriented almost exclusively to the present. She demanded only a utilitarian competence from her medical team and was intolerant of errors. She lobbied for authentic integration of the patient voice,

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believing doing so would prevent medical errors. She genuinely and sincerely viewed compassion as added fluff. While it may be nice to have, she'd explain, it was not necessary for her survival. Her opposition to empathy baffled me.

I had come through the entirety of my illness believing that competency was not at all sufficient. I maintained that medicine could not heal in a vacuum, that it required empathy, and connection. I fervently wanted more humility in my profession. In contrast to her laser focus on the present, my focus was generally either the past or the future. I had entered a kind of covenant with redemption narratives. I believed that by pressing on painful memories, I would access some essential truth that years of training had obscured. I thought I could transfigure the suffering, sublimate it into coherence that would both right the balance of what I'd lost during my critical illness and advance my vision of an aspirational future state. She needed and wanted the change to happen now, where I was content to cast a kite off into some future sky.

Despite beliefs and timelines that were often in opposition, we shared a common purpose in wanting to improve healthcare by fundamentally redistributing power. Like convergent plates of earth that are compelled to move closer, we held each other in place long enough to ask the hard questions. Solid in our respective beliefs, neither of us sunk under the weight of the other. Instead, through friction, some new range of possibility was forced up between us.

She was fashionable with a side of playfulness, where I tended to be plainer and more austere. She loved swing dancing and buying new clothes and would shop for weeks to find the perfect blazer for a presentation, whereas I would pack an entire suitcase of tonal clothing for simplicity. When I arrived to give a joint keynote in all black, she marched me to the hotel gift shop to buy a colorful floral scarf and excitedly showed me eight different ways of tying it.

Though I had experienced more illness and debility than most of my peers, in her eyes I was a novice. The inversion was oddly liberating. It meant that on dark days I could send her a text to that said, "I feel like pulp. There's just nothing holding me up anymore," and know that she would understand. Know that she had probably felt like pulp herself and had long ago accepted it as the consequence of inhabiting a body. There wasn't a thing I could tell her between living and dying that would have fazed her.

"Ok, so now tell me, what's this pulp thing about?" she'd ask, smiling through the phone. And all the thoughts I didn't know I was holding in some kind of cognitive suspension would come pouring out, filling the space between us.

"I don't know," I said, "Maybe I did the math wrong. When I found out about the cancer, I just gave them whatever pieces of me they needed to take. You know, I just like laid it all out at some operating room Alter, like a sacrifice I was trading for more time. And I don't know, maybe there wasn't enough support left behind to hold me up. Maybe the ledger of losses and gains isn't balanced anymore. So, now I'm just pulp."

“You’re feeling a little hollowed out right now, and that’s a hard feeling. It will pass though, it usually does,” she offered, leaving space for me to cry.

“The thing is, I don’t want to find, I don’t think I *can* find any lessons in this. Too much has happened, and I just don’t sense a forward trajectory anymore. You can’t make anything out of pulp,” I said.

“I want you to hear me say this. You don’t have to make anything out of this. Not for anyone,” she paused. “But you might, because it’s what you know how to do, it’s who you’ve been. You make beauty and sense out of terrible, difficult things.”

I reiterated that I was pulp now and that I planned to stay pulp forever. In fact, I now believed my job was not to transfigure the pulp, but to find a home there, in the sticky potage of what I had been.

“Oh sure, you can stay in that soup if you want to. Consider this permission to not be anything other than what you are. Hell honey, just surviving is enough. You are enough,” she said.

I considered her suggestion that there was nothing more to find. That I could allow myself to return to and remain in a more essential and natural state. Half my heart believed her, the other half was wondering what form the pulp could take.

Quickly and without warning, she dissolved into a uremic underground world, where she believed she was part of a government conspiracy. I stood helpless, as the scaffolding of her sanity collapsed. She would tell me later, when she returned from the cavernous hollow of her delusion, that she had stayed focused on trying to crack the code, studying the movements and actions of each facsimile of family and friend who entered the room. She believed that was the only way out. It was a completely terrifying experience devoid of any reassurance from her team. It almost sounded as if she were arguing for more compassion in her care.

“What if I told you,” I said, “that in the ICU, we tell families that uremia is a pleasant way to die? That they should feel at peace, deciding to stop dialysis on a beloved parent or spouse, because it is a good death.” I cringed, waiting for her response.

“Well, isn’t that interesting,” she sighed, and in those words, I felt how fragile knowing could be when it’s not built on a foundation of actual lived experience. How easily the sand of my words could be blown away by her sigh.

“Is it possible,” she wondered aloud, “that you all might be describing the death from your own point of view? That a bloated, but quiet patient slowly dying of renal failure was not a burden to you emotionally. Easy for you should be easy for me.”

That was her way, heating the handfuls of shapeless sand passed between us, melting it into absolute transparent clarity. And despite the window her words afforded me, I still felt as if I were entering a dark, unmappable woods, where none of what I'd been taught was of any value. I had a deep somatic sense that to survive in the new place, I'd have to rewild, relearn how to trust the physicality of an experience.

"Maybe the pulp is a good thing for you," she offered. "Maybe it will let you seep into spaces that weren't accessible before, like a mountain turning into mud."

The goal of our friendship was never agreement. Rather, it was one of allowing space for disagreement while still willingly entering the perspective of the other. The clearing that emerged in the space between us was the most authentically generative ground.

The day she died, a large cardboard box was delivered to my porch, with her name and return address. I set it on the kitchen counter and stared at it, as if encountering her in a new form. I was not at all ready to regard the contents, knowing it would bring our final conversation to an end.

When I unpacked the box, I found an ivory dress with a colorful banded waist, a delicate floral coat she had worn on a trip to the Netherlands, and a locket and a small note written in shaky, uremic handwriting, *I love you always*. Realizing I was wearing all black and she was still editing my wardrobe, I exhaled deeply, and an unexpected guttural sob emanated from my throat.

And then, like the sea under the pull of the tide, I felt her receding until she was gone. I felt the tear of pieces of me that went with her, and the swell of the pieces she'd left behind. ■

## **Biographical note**

Dr. Rana Awdish is the author of *In Shock*, a critically acclaimed memoir based on her own critical illness.

A pulmonary and critical care physician, she serves as the current Director of the Pulmonary Hypertension Program at Henry Ford Hospital. She also serves as Medical Director of Care Experience for the System, where she has integrated compassionate communication strategies and Narrative Medicine practice into the curriculum. She is board-certified in Internal Medicine, Pulmonary and Critical Care Medicine.

## SEEING WHOLENESS

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**KEYWORDS:** Transformation, Wholeness

### OCEAN WATER

**W**e were a relatively large family of four children, keeping my parents ceaselessly busy. Nevertheless, my parents would manage to take a week of vacation once every few years to go down to Mexico. During that time, my grandmother and aunts would take care of the four of us. We would be giddy, without the usual after-school routines and restraints. We would run noisily around the house and empty a package of Chips Ahoy! cookies in one evening.

When my parents would return tanned and smiling, my father would pull out little bottles from his suitcase. He would explain that he had filled the bottles with ocean water and sand. After a brief moment of wonder, we would set the bottles on the bookshelf at the head of our beds and continue to play.

The small bottles of ocean water impressed something upon me, but I didn't know what. Reflecting on it now, it was that I was holding both a piece of nothing and something: this was simultaneously just water and an entire, vast ocean. It was my father's will to share, to impart and connect which turned the water into the ocean.

Today, in thinking about my transformation in medicine, those little bottles come to mind. My incremental, transformative moments in medicine are too numerous to tell; therefore, I offer this brief essay instead.

My hope in doing so is that these words will provide you solace and help dispel the self-critical fog that surrounds many of us.

## **POLARITY**

I would have to say that in this moment, when I think of transformation in my medical career, I do not see a well-delineated change nor a defined process. I see my physician-self as a dynamic ocean, with waves crashing on a calm body of water.

The waves are the destructive emotions and thoughts that I have had throughout my training and practice. They are my perfectionism, severe self-judgment and self-doubt. They are my internal criticism at my lack of efficiency, lack of knowledge, lack of judgment, at my inability to learn from my mistakes. They are my thoughts of non-belonging to medicine, of being a failure, of being too fragile, of being indecisive.

The waves can grow big and become threatening. They can also grow small to the point of being imperceptible. The storm can rise in a flash, and it takes a long time to calm down. Despite it all, and contrary to the instability I feel when the storm comes, my internal drama is contained. That is where the body of water comes in.

Underneath the waves, there lies a radiant depth. It represents my growing understanding that my approach contributes positively to the lives of patients. That the unachievable truth and the inescapable uncertainty of medicine are not my fault. That my respect for the wholeness of patients and concern for their well-being sometimes has the ability to heal brokenness, though it does not heal illness. That deep respect and compassion are true medicine, not soft nor weak medicine. That striving to treat myself with respect and compassion is a journey, and that adapting my practice to my values and limitations is a commendable first step.

Thus, despite the sheer power of the waves, there is an underlying, perseverant calmness. Recognizing this dichotomy, and allowing the bad to dissolve into the good rather than the other way around, has taken quite a bit of transformation.

## **ESSENCE**

If I try to pinpoint which events have led to this transformation, I am unable to. The narrative of my transformation is a sprawling forest of individual stories. Each story is as important as the next and they are all connected by their roots. They are stories of physicianship, motherhood, friendship and partnership. In considering the wholeness of my experience, my best offering in this moment is the essence of my transformation.

Transformation is  
Setting boundaries  
Instead of being crushed by what I cannot hold.

Transformation is  
Accepting that not everyone wants help  
Instead of bestowing help on everyone.

Transformation is  
Knowing that my intentions matter  
Instead of thinking that only outcomes do.

Transformation is  
Recognizing when I am struggling  
Instead of ignoring my mounting discomfort.

Transformation is  
Accepting that I need to change  
Instead of insisting that perfectionism serves my patients well.

Transformation is  
Staying quiet  
Instead of uttering unnecessary words.

Transformation is  
Seeing my wholeness  
Instead of only my brokenness.

Thank you. ■

## **Biographical note**

Sandra Derghazarian is a neurologist and a coach for healthcare workers. Her greatest aspiration is to advocate for kindness and forgiveness in personal and professional everyday life.

## WORK AS A SPIRITUAL PRACTICE

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**KEYWORDS:** Mindfulness, Spirituality, Whole Person Care

**T**he theme of this volume, personal transformation, invites me to reflect on the purpose of my work. After 32 years of thriving in academia it is timely for me to look in the rear-view mirror – now that I am retired. I will share seeds planted and guiding stars that helped me change from an ambitious clinician-researcher determined to obtain tenure in a respected, albeit rather conservative, medical school to a person who dreamed of integrating mindfulness practices into clinical practice and medical education.

The seeds sown in my youth were many. As an avid reader, I was influenced by philosophers and poets who opened my mind to the possibility of finding a Path within oneself and a Way to live it authentically. Dr. Jung, the Swiss psychiatrist-psychologist intrigued me with his book *Memories, Dreams, and Reflections*. His notions of collective unconscious, archetypes, dreams, and symbols of transformation invited me to seek an inner life. Emily Dickinson modeled how a woman could live life her own unconventional way. During my search for a place where I belonged in this world Krishnamurti's wisdom guided me. He wrote, "It is no measure of health to be well adjusted to a profoundly sick society." This idea validated messages I was absorbing at the time (1970's) from the women's and civil rights movements, the motto "Make love not war!" and the Beatles messages via songs (e.g., *Let It Be*; *The Long and Winding Road*). Ram Dass' book *Be Here Now* \* propelled me to venture to India where I discovered Auroville – an UNESCO-recognized international city. There the Oxford-educated revolutionary mystic Sri Aurobindo and his collaborator, *la*

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\*What impressed me while reading this book at 18 years old was how it emphasized self-discovery, confronting societal conventions (i.e., examining illusions), and Dass' description of the Buddhist Eight-Fold Path. Recently I reread it, 50 years later and was surprised to see how its Truth still resonates with me.

*Mère*, encouraged people like me (young and idealistic) to bring consciousness into everyday life. Satprem's book *Sri Aurobindo or the Adventures of Consciousness* called us to, "find the perfect harmony of East and West, of inner freedom and outer mastery." Spiritual seeds were planted; they would sprout and blossom only later when conditions in my life were ripe. Alas, I needed to return to the West and find out how to actualize what I had been exposed to.

After what my father called "my sabbatical" I returned to university to eventually earn a doctorate in Clinical Psychology with a speciality in Mind-Body Medicine. The choice of profession fit my desire to understand how people could discover themselves and reach their full potential. It was also a continuation of what I experienced in my travels. Yet, the demands of school and my fear of failure (which would cast me adrift in a society where I did not fit in) led to a period that obscured the Way of life promoted by Ram Dass and Sri Aurobindo. It was as if I could no longer see the stars guiding me even though they were there in the dark. I felt compelled to succeed in the conventional sense and needed to resolve inner conflicts before I could revisit my spiritual aspirations.

If I had to put my finger on what enabled me to return to who I was when I traveled the globe for five years it would be when I mail-ordered meditation audiotapes and books such as, *The Varieties of Meditation Experiences* by Dr. Goldman, who had studied in India in the same ashram as Ram Dass. I had been fascinated by the early empirical studies showing yogis controlling body reactions (e.g., blood pressure, temperature) in ways not yet understood by Western scientists. Dr. Goldman, along with the Harvard cardiologist, Dr. Benson, explained how this could be done in his classic book, *The Relaxation Response*. Mind-body links were being observed as the technological means for measuring them emerged. I trained in a pain clinic that employed hypnosis and wondered about the similarities and differences between these "mind tools." As I gained a deeper understanding of the importance of the psyche for patients with chronic pain and illness, I aspired to not only treat patients but also teach physicians the importance of psychosocial factors for patient outcomes. If relief of suffering was our mutual goal, then our work could be a spiritual practice – i.e., acts of compassion. Many physicians throughout history have exemplified this ideal (e.g., Drs. Albert Schweitzer, Paul Farmer).

My professional trajectory took a turn when a proposal written by Dr. Mount about Whole Person Care landed on my desk. I thought that my interest in patients with chronic illness could complement their focus on palliative medicine. I had an epiphany: this emerging group of like-hearted colleagues could provide the soil where mindfulness work could be cultivated. It became the ground for the Aurovillian seeds to sprout. After Drs. Mount, Hutchinson and I took a road trip to OMEGA (a retreat center in New York) to take Kabat-Zinn and Santorelli's mindfulness course, our journey together began.

I had to practice what I wanted to teach (i.e., mindfulness). Thus, I meditated in Zen centers, continued my training with Kabat-Zinn and his colleagues to become a certified Mindfulness-Based Stress Reduction



(MBSR) instructor. I attended Vipassana and Insight Dialogue retreats for years. Gradually, I gained insight into the processes and true purpose underlying meditation. Mindfulness, contrary to the current zeitgeist, is not a technique; it is one of eight steps on what Buddhists call the Noble Path. By teaching MBSR, and later Mindfulness-Based Medical Practice year after year I gained a deeper understanding of how and why this approach to life was beneficial. By conducting research and writing papers on the topic I deepened my own understanding. Being naturally curious, I continued to learn from the Masters (e.g., J. Goldstein, G. Kramer, HH the Dalai Lama) by reading. Their words elucidated my experiences. Vipassana is “insight meditation”; by observing one’s inner experiences (mental and physical, and the links between them) cause and effect (karma) is understood. One sees with clarity universal truths about being human. Over time, I became less anxious, more patient, better able to listen deeply while gaining insight into the causes of suffering. Compassion emerged naturally. Observing patients’ positive outcomes following mindfulness programs elicited sympathetic joy in me. I was passionate about sharing what I was learning. Why? Because living fully in the present moment (Be Here Now) has the power to transform lives. I was able to relax into the work rather than be driven by it. I used my creative energy for the good of others. I was grateful to have come home, at long last, to an inner as well as outer place where I belonged. The confluence of these experiences enabled the Aurovillian seeds to finally bear fruit.

This was an exciting time as we were at the forefront of something yet to be accepted in mainstream medicine. We designed mindfulness programs for patients, physicians, and allied health care professionals. We experimented with different workshop formats (half-day, full-day, weekend) to reach as many clinicians as possible. We published papers, book chapters, and books to share our insights. I taught fourth-year medical students MBSR for several years. This led to the adapted Mindful Medical Practice course that is currently part of the second year of medical students’ curriculum (Drs. Liben and Hutchinson, along with others designed the final course).

After my sabbatical leave in Paris where I taught MBSR to clinicians and patients, I was given a green light to leave the McGill University Health Center Research Institute to devote myself fully to Whole Person Care. I was free to publish commentaries that drew on literature for inspiration (e.g., *The Heart of Healing*). I attended a workshop at Columbia Medical School to learn Narrative Medicine techniques. This enabled me to publish the edited book, *Mindful Medical Practice: Clinical Narratives and Therapeutic Insights*. For eight years I invited authors to share ideas while editing the *International Journal of Whole Person Care*. Employing Narrative Medicine techniques, we published a special volume in January 2021 highlighting clinicians’ harrowing experiences on the front line of COVID-19. Recognizing that most clinicians could not attend eight-week mindfulness programs, I provided a Physician Wellness program sponsored by the Department of Medicine. The MUHC Wellness Task Force was formed during the pandemic to offset the stress caregivers experienced on the front lines. We offered an online workshop entitled the Four Pillars of Wellbeing. Currently we lead Schwartz Rounds that provide a sense of community for physicians and other staff in our hospitals.

Now, as a member of a program for retired McGill professors I will continue to serve the institution that provided me with not only a wonderful career but a sense of purpose. How grateful I am for the journey that led me to McGill Programs in Whole Person Care which fulfilled my aspirations born in an international city (Auroville, India) where one's work was a means to embody spiritual longings. I was able to maintain a sense of belonging while touching others' lives in ways that helped them lead happy healthy lives. This is my definition of work as a spiritual practice. ■

## **Biographical note**

Dr. Patricia Lynn Dobkin has been a family member of McGill University since her undergraduate years. She obtained a PhD in Clinical Psychology in the United States and returned to McGill University as a Post-doctoral Fellow. She taught Mind-Body Medicine and conducted clinical trials of psychosocial interventions for patients with chronic illness as a member of the Division of Clinical Epidemiology, at the McGill University Health Centre Research Institute. As an Associate Professor she joined the McGill Programs in Whole Person Care where she launched numerous mindfulness-based initiatives including programs and workshops for patients with chronic illness and health care professionals. She served as the Editor of the International Journal of Whole Person Care for 8 years. Currently, albeit retired, she is a member of the McGill Department of Medicine Wellness Task Force that provides physicians with initiatives that enable them to thrive in their profession.

## THE ENDS OF THE EARTH...EVER BEEN THERE?

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**KEYWORDS:** Transformational experience, Storytelling, Artistry, Healing spaces

In 2018 it was as if my pilgrimage as a doctor had come to arrive at the ends of the earth. In Latin, Finisterre. Finisterre, the place where ground turns to ocean. Finisterre, the uniquely chosen sacred final destination of the Camino de Santiago de Compostela; a 780km pilgrimage in southern Europe ending in Spain. Ending in Finisterre, if you choose to press on past Santiago for 3 days of walking to the rock cliffs of Finisterre overlooking the Atlantic. The place where ground turns to ocean and if you wanted to walk onward it would not be possible to continue in the way you had arrived by foot. Finisterre is a place for contemplation, transcendence, and vulnerability. I had arrived at my figurative Finisterre in my career.

Perhaps you have come to a place in your career path that stopped you in your tracks and forced you to consider how it was that you had arrived in this place. Arrived in this state of being a doctor. The years go by so fast. How was it that you got here? Perhaps virtues that once guided you through medical training and the first years of practice are no longer able to buoy you this place in your career. Perhaps you haven't had a moment to catch your breath and consider the virtues that guide your career. Perhaps the conversations of life you are having are ending or are already ended and you are just now realizing this new reality. Lastly, perhaps you have arrived at a place in your career path where it was time to let go of the things that helped you travel thus far. Far enough to arrive in this place where you find yourself. Perhaps it is time for letting go? A time for change. Perhaps change has happened and you are just realizing it now?

I didn't know it then but 2018 was my arrival at my career's Finisterre. A doctor for 18 years, and the end of the earth in my career experience at that moment in time. The place in my career where the ground beneath my feet felt unsettled and the future was unknown and there was no way to travel onward. And similar to walking the Camino de Santiago and arriving in Finisterre, there were three real rituals that I was performing, but I did not realize it so clearly at the time.

The Camino de Santiago is marked with scallop shells as signposts. Scallops are a sign giving direction and so upon arrival at the Ends of the Earth the first ritual is to contemplate what brought you here. While eating tapas of scallops consider the direction of your life and what has contributed and led to your arrival at the Ends of the Earth. The second ritual is to burn something you have brought; perhaps a love letter, a greeting card, a picture, or a tightly held belief that may no longer inform the conversations of your life. The third and last ritual is to leave behind something that brought you here but is no longer needed to carry you forward; perhaps a pair of shoes or socks. How then will you journey onward, the way only your shadow could take to your unknown future? So, three rituals I consider to be contemplative, transcendent, and vulnerable. Being contemplative of what brought you to this place while creating transcendent ashes of once important messages now traveling in the air and experiencing the vulnerability of letting go of the safe and familiar travel accompaniments. In my lived experience at my career's End of the Earth these rituals are not linear. These three rituals serve like a call and answer, and sometimes the answer is the call echoing across the waves. Rather than an answer, you are simply called deeper into the unknown. In 2018, I said goodbye to three mentors who had helped me to this place in my career. The virtues they instilled could carry me no further. I was appreciative to have had the relationships and fearful to let them go. There was certainly no way for them to help me move forward. In fact, in retrospect the conversations we were having, or I thought we had been having had ended some years before. It was only now in 2018 that I felt this deep

### **Finisterre\***

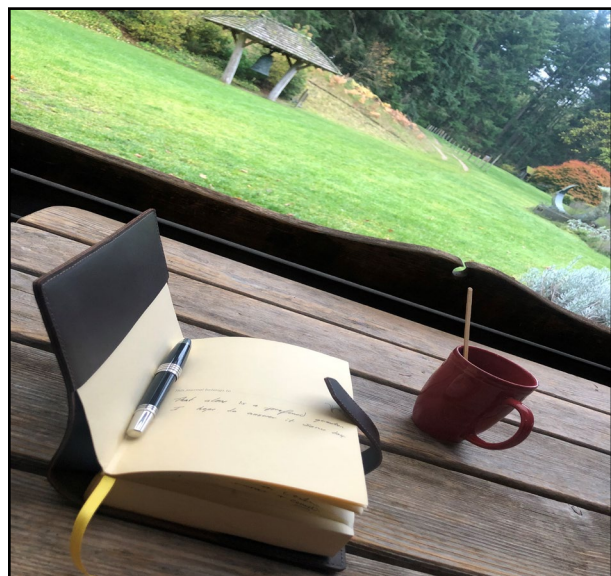
The road in the end taking the path the sun had taken, into the western sea, and the moon rising behind you, as you stood where ground turned to ocean: no way to your future now except the way your shadow could take, walking before you across water, going where shadows go, no way to make sense of a world that wouldn't let you pass, except to call an end to the way you had come, to take out each frayed letter you had brought and light their illumined corners; and to read them as they drifted on the late western light: to empty your bags; to sort this and to leave that; to promise what you needed to promise all along, and to abandon the shoes that brought you here right at the water's edge, not because you had given up but because now you would find a different way to tread, and because, through it all, part of you would still walk on, no matter how, over the waves.

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\*David Whyte, *Finisterre, The House of Belonging*, from *David Whyte: Essentials*. ©2020 David Whyte. Reprinted with permission from Many Rivers Press, Langley, WA. [www.davidwhyte.com](http://www.davidwhyte.com)

in my core being. The reason they could not help me move forward was because the direction I was moving was not mine anymore. The frantic career development pace was a blur. I had become so caught up in all that I perceived was expected of me that I lost sight of what it was I wanted to do in life in the first place. There was just so much noise. It was a poignant time and I remember feeling failure, joy, relief, guilt, and betrayal all at the same time. They had helped guide me here and yet the virtues of those relationships could no longer carry me forward because those virtues were theirs, and never really trusted traveling companions of mine. Those virtues had become foreign to me. I honored their guidance in getting me here like the clam shells along the Camino, but I had to burn their letters, realize the conversations were stale and over, and say goodbye. Farewell. I had to revisit what was important to me. Why medicine? Why hospice and palliative care? Why at an academic medical center? Why me? Why now? Why ever?

In November 2019, in search of how I was to tread forward, I joined an eclectic small group of people from all backgrounds and from all around the globe at the Whitbey Institute on Whitbey Island off the coast of Washington state for the first of 3 three-day retreats over the next 2 years on Conversational Leadership<sup>†</sup> with poet David Whyte. Three days of gathering, listening, sharing, contemplation, writing, small group activities and sharing with the focus being the 7 core steps to conversational leadership. I awoke each morning around 4am and read and wrote for a couple of hours based on the material for that session over a cup or two of coffee while sitting



in the 40-degree damp northwest pacific air at a picnic table outside the retreat center. We started every morning with piano music and Tai Chi, followed by poetry, story and sharing sprinkled with art inspired large and small group activities to promote deepening awareness and experience of the themes. We spent time in the retreat center and outside in the natural beauty of Whitbey Island.

Conversational leadership is lived artistry that is discovered through seven core elements to guide you in developing your artistry; for me, my artistry in creating safe, welcoming spaces, and crafting language to promote healing and wellness. This stands in stark contrast to the strategic mindset of my career focused on tactics for achievements. Artistry

The seven elements are not linear but dynamically fluid and they are: Stopping the Conversation, Cultivating a Friendship with the Unknown, Coming to Ground, Cultivating Robust Vulnerability, Artistry, Making the Invitation, and the Harvest of Presence.

<sup>†</sup> Conversational Leadership is transformative (<https://www.invitas.net>).

describes my way of being and my way of showing up in the world as a modality for doing rather than simply a strategic mindset for doing and achieving. Artistry is strategically relational.

Before the first gathering, David extended one of the most enriching invitations; David invited us to study the work of artists who were an inspiration in our work. As an aspiring photographer, writer, and storyteller, I chose documentary filmmaker Ken Burns because Ken Burns focus on the richness of emotion in his stories. Ken Burns exemplified the dichotomy between the subject and the story. His subjects (e.g., Civil War) were always told through story. Emotional stories. Translating what I had discovered from teaching communication in healthcare, the subject was communication, the delivery was story. The emotion of the story is what conveyed the subject matter.

My study of Ken Burns led me to study a whole host of storytellers/artists with some of the most impactful being Malcolm Gladwell, David Sedaris, Annie Leibovitz, Ron Howard, Jodi Foster, Steve Martin, Michael Crouser, Vivian Maier, John Mellencamp, Bruce Springsteen, and Maude Lewis. What inspired me most was their perspectives on what I have come to recognize as *emotional archaeology*. In other words, uncovering, discovering, examining, contemplating, and sharing stories through the emotional experience of story through spoken word, imagery, written word, song, music, videography, and any other medium that best expresses the emotion of the lived human experience. What also inspired me was their courage to be vulnerable and take risk in their career to ensure that they could cultivate their artistry true to their core being.

Why do I care about stories anyway? Perhaps because I am still discovering my own. I took time in the early hours before the retreat started to journal about what matters and crafted the beginnings of a list of virtues that would carry me forward: humility, curiosity, generosity, love, kindness, joy, authenticity, presence, prayer, listening, and sincerity. Unknown to me at the time, I was starting to cultivate my artistry – the gift that I offer those around me that keeps on giving. What is my artistry and how would I (re-)discover my artistry was core to this transformational process and my being. I would need to take risks to refocus my life and career. Artistry is core to how I show up in the world. Once again it is a way of being.

Perhaps you have enjoyed time in retreat or a contemplative pilgrimage like the Camino. Times in retreat and contemplation are often brief and separated by what seems like too much time. Even though I have yet to journey on the Camino, I now journey every day in my career as though I am on a contemplative path trusting in the signs leading beyond the horizon, resting in the moment, and letting go what becomes too heavy to carry forward as I sort through my vulnerabilities to be present in the world. Here is how I translate Conversational leadership to my daily cultivation of my artistry and my way of being in life.

## **STOPPING THE CONVERSATION**

What conversation are you having now that you need to stop? I had several conversations that I just needed to stop having. In fact, the noise of all the conversations was at one point too much noise to even be heard. Those tended to be conversations of delayed gratification. When I achieve this, I will do that. How do I achieve this or that? How can I make it go faster or slower? Today as I journey the Camino of my career, I am keen to recognize who is speaking, who is listening and how the conversations are experienced. I speak less and I stop all together when nobody is really listening. I listen more. I move on when I want and stay longer when a real conversation is being held. I am more intentional about who I bring to the table and who I do not.

What promises are the pillars of your existence? One promise I needed to break was a promise of obligation. In stopping my conversations with my mentors, it was a radical letting go of promises made and now broken. I misinterpreted the stale conversations and took missteps and I felt vulnerable. I felt crumpled up and thrown away. As I mentioned, I remember feeling failure, joy, relief, guilt, and betrayal all at the same time. I learned that being on a threshold of where your life is and what you want now is about the conversation between who you are and who you are becoming. What promises do you need to break? Avoid the temptation to make new promises too quickly.

## **CULTIVATING A FRIENDSHIP WITH THE UNKNOWN: ASKING A BEAUTIFUL QUESTION**

How many packs of obligations do you carry on your journey? How heavy are they to carry? How many have you set down by stopping the conversation? Let them go. Set them all down along the path and rest. Just, let them go. Have you ever been exiled? I felt exiled when I said goodbye to my mentors, and it was in that moment that I realized I have just 3 choices. I could carry on and deny it and act like nothing had happened. Which I did for a long while. I could become cynical like the strategic mind will direct you and lead conversations of frustration. Which I also did for a long while. Or I could look deep inside myself and find a place where my voice could once again carry volume and meaning. Which I do now. And once I was able to speak of my exile, the path home became clearer. These days I travel my career Camino with a light pack and a fresh voice always considering my artistry and what questions are calling to me that I need to speak into the world with my ever-regenerating voice. I have something to say, and you do too.

## **COMING TO GROUND: MAKING CONTACT WITH THE COURAGEOUS CONVERSATION**

In the silence created by stopping the conversation, what new ground will you discover? What step will you take? I would recommend not stepping too soon. There is plenty of life and career ground to cover by

standing in place and surveying all that is around you. Be aware. Slow down. Be intentional about your next step and pause not once but many times before you set your next step firmly on new grounds. Rest in the quiet and do not hesitate to leave the load and travel on with only the essentials of a day pack. That is enough for today. Keep it simple.

## **CULTIVATING ROBUST VULNERABILITY: ASKING FOR VISIBLE AND INVISIBLE HELP**

What are your vulnerabilities? If you fail, who would you be? Ask those around you about your vulnerabilities and if they are honest, they will tell you. Acknowledging your vulnerability has a quality of surrender and may be a behavior that runs counter to the prevailing culture and norms. Be brave. Have courage. Humility and curiosity help to cultivate a softening and gentleness that allows for the acknowledgement of your vulnerability. Like exile, find your voice and speak your acknowledgement of vulnerability into the world. Daring to bring your vulnerability into relationship is the invitational nature to request help both visible and invisible.

## **ARTISTRY: FOLLOWING THE PATH OF VULNERABILITY AND REVELATION**

How will you find your own physical practice of this artistry that you offer as you journey on your career Camino? What gift will your presence and engagement offer to others that will keep on giving long after the conversation has ended. For me it is solely based on the virtue of generosity. I am perpetually reflecting on the invitation I am making to others to create space and language to foster healing and well-being. Core to this is the awareness of emotional archaeology informing the experiences and memories that we all may live and relate to. This is the focus of my artistry by being just brave enough to speak my vulnerability into the world if only for a moment.

## **MAKING THE INVITATION: THE CRUCIAL MARKER OF A REAL CONVERSATION**

What invitations are you making? Are you too busy to be bothered? Are you too strategic to be interrupted to consider a new thought or way of approaching an issue? For me, the question is, "Cory are you being generous with your time, presence, and expertise with a listening ear and a humble and curious mind?" For me, I want my invitation in life to be foundationally rooted in virtue of generosity. That was not a virtue guiding my being in previous season of my life or career. The seasons of our life come with invitations. Consider the invitations that you are making to those around you. Invitations are a way of risking ourselves;



being vulnerable. Consider the conversations that flow from these invitations. My conversations are richer and informed with attention to emotional archaeology.

## **THE HARVEST OF PRESENCE**

Are you living a life of conditional waiting or delayed gratification, awaiting dying as a sign for the harvest of your life or are you harvesting during living? I harvest the beauty of my Camino of life every day. I do not need to await a retreat or a trip to Spain. Although, I hope to walk the Camino someday. I harvest generosity and joy with the conversation with a nurse to care for a patient, the listening to a patient or family member, conversations at the dinner table, or the cheers from the sideline of the soccer field. Are you putting valued plans on hold, waiting to have enough money, enough time, fewer children at home, more children at home, or are there other barriers that are holding back your abilities to harvest in the present? Are you being too strategic? The time is now.

## **CROSSING THE UNKNOWN OCEAN**

I dismantled the strategic mindset that had occupied my first 18 years as a doctor and now am living more fully in the poetic mindset with attention to my artistry now 23 years in and it has been transformational. For me, the strategic mindset is outcome focused like a horse at a racetrack with blinders striving to achieve without notice of those around you. The artistic mindset is a different strategy that rests in an abiding trust that the outcome will be achieved in one form or another and essential to that outcome is the experience of those working together towards that outcome. Artistry as a way of being is for life, not just my career. There is no difference in my way of being in my career and in my personal life. Life is grounded in a poetic mindset with attention to my own artistry. The most important influence on my medicine came from the humanities and not medicine. I was able to stop the conversations of my life that were no longer contributing to who I was becoming 18 years into being a doctor. I spent a great deal of time wrestling with the unknown. Should I leave medicine? Should I leave for a different institution? What should I do about cultivating my artistry and how will my environment respond? I came to terms with the courageous conversations of my life and cultivated my abilities to acknowledge my vulnerabilities and speak them into the world as invitations for visible and invisible help. Through new conversations people helped.

I burned virtuous notions of fame and promotion and rested my soul in the humanities of caring and being. Less is more. I defined my artistry as creating healing spaces to listen to the rich textures of stories and to craft language of healing and well-being. I made many promises, and one is simply to be generous and hopefully inform the invitational nature of my being with generosity. I journal daily and I harvest the new direction of my life aligned with artistry and through close attention to emotional archaeology through my personal life, clinical practice, leadership, research, and teaching.

Like the call and answer, some calls are still echoing, and I am listening. I have new conversations and mentors that are truer to my virtues. I encourage you to consider discovering what it is you may need to live more fully in the world because there will always be more questions patiently awaiting you. What virtues inform your life? What invitations are you making? Are you humble and curious? What is your artistry? What would be on your beggar's board if you lost everything? What conversations do you need to stop? What conversations are you having that are already over? Are you in exile? How will you return home? From where will your voice speak? Will you speak your vulnerabilities aloud in search of help? What promises do you need to break? What packs of obligation do you need to set down? What are the essentials for your day pack? What will you harvest today? In my experience, these questions and others will serve as constant companions on your Camino and are the tools that emotional archaeologists use to cultivate their artistry and bravely examine their way of being. ■

## **Biographical note**

Cory Ingram, M.D., M.S., FAAHPM, is a Hospice and Palliative Care Consultant at Mayo Clinic. Dr. Ingram is the Director of Quality for Mayo Clinic Hospice and the Quality and Safety Curriculum of the Hospice and Palliative Medicine Fellowship. Dr. Ingram also shares his expertise through teaching as an assistant professor of both Palliative Medicine and Family Medicine with the Mayo Clinic College of Medicine and Science and a Co-Director of Communication in Healthcare in the Program for Professionalism and Values. Dr. Ingram is a fellow of the American Academy of Hospice and Palliative Medicine and has served in multiple capacities in the humanities and is the Editor in Chief of the AAHPM Quarterly and in his tenure, they are launching an *Artist in Residency* section to the publication. He has been featured at the Canadian Virtual Hospice and holds Storytelling workshops with Canadian health care institutions. Dr. Ingram is currently working with the palliative care units in Ottawa using the 55-Word story as a modality to improve meaning, purpose and quality of life. He is also a published photographer and poet.

## ON LIFESAVING CARE AND THE NECESSITY OF DIGNITY

### The story of Mrs. Hassan

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**KEYWORDS:** Whole person care, Patient, Medicine, Surgery, Dignity, Empathy, Transformative,  
Medical student

**A**s a medical student in your early months, it's difficult to disagree with the notion of whole person care. Of course, all doctors should see the patient before them not as a biophysiological problem to be solved, but as a person with a family, friends, a sense of self, a sense of dignity. This seemed so obvious as to be almost banal, and I often took these lessons for granted. This changed – quickly and dramatically – when I began the clinical stage of my training.

The transformative experience I wish to discuss involves a patient I will call Mrs. Hassan. Mrs. Hassan was a librarian in her early sixties, almost the same age as my mother. She had a reserved demeanor and spoke French with an accent. The first time I saw her, she was unconscious.

One surprising thing about operating rooms is how cold they are. It was my first time on the surgical side of the OR (I had been in anesthesia the month before), and I felt that distinct blend of caffeine-induced focus and early-morning fatigue. I clumsily scrubbed in, amid a buzz of orderlies, nurses, residents, fellows,

and other medical students. In the OR's austere environment, under harsh fluorescent lights, with the continuous beeping of monitors, and, like many junior medical students, in perpetual fear of contaminating the sterile field, I felt a combination of trepidation and excitement. Mrs. Hassan was having a major esophageal cancer removed in one of Canada's best tertiary hospitals – the case was bound to be interesting. The attending surgeon strolled in when everything was ready, the patient under general anesthesia and the trainees eagerly awaiting instructions.

For the first 45 minutes, I watched in awe. For the next four hours and 45 minutes, I tried not to zone out. The surgery was technical, performed with great skill using a relatively new, minimally invasive technique. The operation was successful, the tumour was removed, and when it was over, I watched Mrs. Hassan wake up in the post anesthesia care unit.

A few days later, I was asked to present Mrs. Hassan's case at Friday rounds. Her surgery was the first I had witnessed, and she was the first patient I had ever presented. I summarized the history of her illness, her presentation, the surgery, her status post-op. While I had not contributed to her care in any meaningful way, I felt in some sense responsible for her – I knew her story inside out. She was "my patient."

Mrs. Hassan remained in the hospital, making an uneventful recovery. About a week after the operation, however, her X-ray showed a distended stomach, a common complication but one requiring prompt attention. It was decided that a nasogastric tube (a small suction device passed through the nose and into the stomach) would be placed to relieve the pressure.

A small herd of medical trainees entered Mrs. Hassan's room. There were two fellows, a resident, two other medical students, and me. Mrs. Hassan was discouraged by the news of the procedure but resigned to its necessity. I wheeled in a screen attached to a gastroscope, which would be used to visualize the patient's stomach. Another medical student sprayed lidocaine into Mrs. Hassan's mouth and nostrils, standard practice to mitigate the discomfort of the nasogastric tube insertion.

Mrs. Hassan was alone in her bed, surrounded by observers. I was to her right with the two other medical students. Facing me was the resident, who would perform the procedure under the supervision of a fellow. The resident inserted the nasogastric tube into a nostril, and Mrs. Hassan gagged. This was to be expected, but I assumed the tube would be rapidly placed and the discomfort would soon be over. Quite the opposite occurred. The resident wiggled the tube around, getting it into Mrs. Hassan's throat and aggressively stimulating her gag reflex, but unable to advance it into her stomach. He then attempted the other nostril as Mrs. Hassan heaved. The fellow watched him, providing tips here and there. No one seemed to be paying attention to her.

As a student, I understand that medical teaching is vital, but there is a time for teaching and a time for experts to take over. Despite repeated, failed attempts to get the tube in, the resident continued to try as the fellow observed.

At a certain point, the gastroscope was inserted. The nasogastric tube already in Mrs. Hassan's nose, the thicker gastroscope was shoved down her throat as she violently choked and retched. I will not forget the way Mrs. Hassan began to clutch, with both hands, the armrest on the side of her bed. It was as if she had to grab hold of something to prevent herself from drowning. Shocking though it was, I was less surprised by the brutality of the procedure than by the lack of attention paid to Mrs. Hassan's pain. As the gastroscope went in, everyone scrutinized the screen I had brought in, attempting to discern what was causing the stomach distension. Fascination with Mrs. Hassan's condition seemed to be blinding the medical trainees to her suffering.

In fairness, the young physicians felt they were doing something good for Mrs. Hassan – and they were. The nasogastric tube was necessary to ensure she successfully recovered from the surgery. Rarely had anything been clearer to me, though, that a lifesaving procedure was no excuse to leave Mrs. Hassan writhing without comfort. No one told her it would be over soon; no one held her hand. To say nothing of sedation, which, I later learned, while not routinely used for nasogastric tube insertion, should be standard practice during gastroscopy.

At some point, I instinctively grabbed Mrs. Hassan's shoulder, telling her she was doing great and it was almost over. It didn't feel special; it felt natural. What felt to me so incredibly unnatural was that I was the only one holding her. Eventually, a nurse came in and grabbed Mrs. Hassan's hand. Noticing the pained look on the nurse's face, I knew immediately that she was seeing what I was seeing.

The fellow eventually took over and the procedure was completed. Mrs. Hassan slumped back into her bed, exhausted, her face awash with snot and tears. The fellow, young enough to be her son, rubbed her head and said, "Sorry sweetheart but we had to do this for you."

There was a small chapel in the hospital. I have never been a particularly spiritual person, but after it was all over, I went to the chapel. It was a novel feeling for me, the sense that I needed to be there. I closed my eyes and silently pleaded that Mrs. Hassan would recover, find comfort, find solace.

In the days that followed, I questioned whether I had overreacted to the situation. I was new to hospitals, after all. Maybe this happened all the time. When I brought up my concerns with the surgeon, he politely dismissed them: yes, these procedures are unpleasant, but given a lack of resources, there is really nothing to be done. Sedation, apparently, was out of the question.

Still feeling a sense of responsibility, I opted to visit Mrs. Hassan a few days later. I found her in considerably better spirits, the nasogastric tube still in but set to be removed soon. I apologized to her for her treatment. She told me it was worse than anything else she had experienced – worse than the surgery – and if they tried to do that again, she would refuse. She couldn't understand how the young doctors who performed the procedure could have behaved like that. We spoke about her grandchildren and her immigration to

Canada. I wished her the best and said I would come visit tomorrow, hoping I had conveyed that someone in that room had seen her pain, had seen her.

In medicine, we sometimes feel that patients should realize there will be moments of discomfort and embarrassment and should accept it. We are helping them, and they shouldn't blame us for doing our job. Yet, while there will be moments of discomfort, there should never be moments of indignity. The most skilled clinicians are not those who use brute force and "give it to the patient straight," but rather those who make the moments of unease seem to pass in a flash.

My experience caring for Mrs. Hassan was profoundly transformative, as it showed me the consequences of not treating someone as a "whole person." The failure to recognize a patient's suffering – either because we have intellectualized their pathology or because we tell ourselves we are just doing what it takes to help them – is catastrophic. I will not forget Mrs. Hassan, and I will see her in the patients who come under my care. She will remind me that patients are people deserving of kindness and compassion as they navigate their stay in a place of healing. ■

## **Biographical note**

Alex Stoljar Gold is a medical student at McGill University, where he completed a Bachelor of Arts and Science in Cognitive Science. Alex is passionate about whole person care, with a particular interest in exploring patients' experience of illness through the humanities in medicine. He is also interested in medical anthropology and global health.

## APATHY SETS IN DURING THE THIRD YEAR

### Lucie Dubes

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**KEYWORDS:** Narrative medicine, Medical education, Psychiatry, Empathy

*I met you on a stormy day. I had already been six weeks into my psychiatry rotation and every shift had been confirming my interest. When I heard a young woman was being brought to the emergency by her friends for depressed thoughts and suicidal ideation, I got excited. I wanted to do that consultation; I love this patient population. When I found out you and your friends were second-year medical students, I wondered how it would affect history-taking and therapeutic alliance-building. I did my best at the interview: I made sure to give you space, to validate your experience, while asking all the screening questions. You are going through a lot and life has not been easy for you. I feel for you and want to help. I leave the room, write my report, and come up with a differential diagnosis and plan. Major depressive disorder or adjustment disorder, I think, is not an acute risk to self or others. We discuss a safety plan, red flags to come back to the emergency room, crisis resources and outpatient psychiatry follow-up. Your friends are upset: "This is all you can do for her now? You are going to send her home to wait for someone to call her in some indefinite amount of time while she is currently in distress? This is impossible, we are not leaving until something concrete is done." I had not seen that one coming.*

I have always been fascinated by stories; particularly when they have a blurry beginning, unclear progress and unfinished ending. I like stories that can be dissected, analyzed and reconstructed. I like stories that offer space for interpretation. I like stories so much that I considered writing before deciding on medicine.

As it turned out, I was better at analyzing them than making them up. More often than not, my favourite part of medicine remains the "history of present illness" and "impression". *This is what I think it is based on what you are telling me.* I remember very vividly, at the very beginning of our first year of medicine, being warned that "Apathy sets in during the third year." *Not for me,* I thought. I felt like if anything, I would always be connected to my patients' stories.

Back to my patient in the emergency, there was a clear mismatch between the stories her friends and I had told ourselves about the patient. To me, this was a patient with a low suicidal risk presenting to an overloaded emergency system with limited services to offer. To her friends, this might have been the first time they had someone close to them experiencing such intense emotional distress as to express wishes to die. Even after clarifying the functioning of the psychiatric emergency system and validating their frustrations regarding wait times for outpatient referrals, I still felt like something was missing. I could not ignore that the voices of these two friends resonated too close to home: they could have been mine a year ago. Yet, it was as if the transition from learner (as a second-year medical student) to provider (as a clerk) had erased my ability to relate to what it meant to be on the receiving end. It was as if now that I was exposed to clinical practice, I could not recall the experience of "not knowing". I was not able to avoid the third-year medical students' fatality, after all.

It required me to make a conscious effort to be able to step out of my own "post-clinical exposure" perspective and understand theirs. I had initially agreed with my supervisor that the friends were "unreasonable." Yet, when he entered the room to confirm the plan, I felt a switch in my perspective. It was as if the naturally existing hierarchy got me closer to the shoes of the medical students, allowing me to understand that what was unreasonable in this interaction, was not their expectations but those of the treatment team. How can we expect patients to understand that an emergency room is for, "stabilizing," "providing acute care," and "triaging" rather than healing? How can we expect them to know that what may have been their first access to care is not able to care for them?

It is in the philosophy of narrative medicine that I started finding answers – not about fixing our broken medical system, but rather about fighting apathy. Narrative medicine borrows from the humanities and arts to provide us, healthcare professionals, with a framework for approaching patients' problems holistically and understanding how their experience of illness and healing may be anchored into a wider narrative, that of their entire life as well as ours.[1] It may be as a medical student, whose life experiences could be closer to that of being a patient, or as an experienced physician, whose experiences may be tainted by the innumerable patients they have treated – and maybe more so by those they have found "difficult" or "challenging." Why is it that some patients make us want to move mountains when others we look forward to closing the door on? It would be a mistake not to understand how our past experiences, roles and responsibilities in the patient's story influence how we interpret it, how we present it during handover or condense it in discharge summaries.



Concretely, there was little else we could have done for this patient. The medical system being what it is, she would have to wait for a call in an unknown amount of time, telling her it is finally her turn to be receiving the care she needs. Yet, I would argue that a lot more ended up being done. My own positionality as a medical learner ended up being a therapeutic ally: I could both validate my patient's and her friends' incredulity while also explain the reality of the field. I gave her a list of mental health community resources as well as private psychiatrists who offered rating scales. It was not much, and still appeared extremely unfair that one would have to spend money to access appropriately-timed care, but the three medical students left telling me it still felt like "something was being done." What they needed was validation that they had done a good thing by coming to the emergency and that their friend was going to get help. The limitations of this interaction were not that of the system, but my very own, in understanding how it was impacting the therapeutic relationship.

Narrative medicine has not only been reported to have a healing power from patients' perspectives but has also been proven to do so medically. Practitioner narrative skills may alleviate cancer pain, reduce disease in rheumatoid arthritis, improve lung function in asthma and heighten immune response following hepatitis B immunization.[2] In addition to providing better patient care, narrative medicine could also offer a way of making us more empathetic toward our patients. By allowing ourselves to enter our patients' shoes, we could better understand their expectations of care, which more often than not may be as important to address as their "chief complaint". As future physicians, we are going to be perpetually exposed to stories, so why not use them to heal? ■

## REFERENCES

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## Biographical note

Lucie Dubes is a 3<sup>rd</sup> year medical student at McGill University. She completed her Bachelors of Arts in Human Biology & Society at the University of California, Los Angeles and worked in clinical research for a few years prior to starting medical school. During her medical studies, she became interested in the Art of Narrative Medicine, and completed the Foundation in Narrative-Based Medicine Digital Certificate at the University of Toronto in April 2023.