### Vol. 11 No. 2 (2024): Vulnerability in Medicine



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# WHOLE PERSON CARE

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### EDITORIAL THE BLACK, WHITE AND GREY OF EMBRACING VULNERABILITY

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#### KEYWORDS: Suffering, Vulnerability, Healing

#### BLACK

ast summer, my wife was sitting on campus eating lunch with a friend and colleague when she sustained a brain stem stroke. We are both professors in our early forties and have two daughters, who were seven and three at the time. The stroke came as a complete shock, with no prior conditions or factors that warned of its possibility. In the emergency room, she was diagnosed with a vertebral artery dissection – a tear in the artery's inner layer – that created a blood clot and brain damage, resulting in intense dizziness, nausea, and motor control impairment. Over the first two days, she was in a fugue-like state, drifting in and out of consciousness, and trying to prevent uncontrollable fits of vomiting by limiting movement as much as possible. It was a truly horrible 48 hours. As her condition stabilized, she started to work with the rehabilitation team to regain basic function, such as eating solids, sitting up, standing and walking. She made good progress over the first week and we prepared for a transfer to a rehabilitation centre – plans that were quickly derailed.

A week after her initial admission she started experiencing an intense ringing in her ears. This prompted another MRI, which confirmed three additional arterial dissections – all the major blood vessels serving her brain were now structurally compromised, but thankfully (and remarkably), there was no further neurological damage. Further tests were ordered, and further complications were revealed. She was diagnosed with a

renal infarct, stemming from what seemed to be spontaneous deformities of the main arteries serving her gut and kidneys. A couple of days later, blood work and heart monitor readings suggested an additional (small) dissection in her coronary artery. Not good. But thankfully (and remarkably) these additional diagnoses didn't come with new lasting symptoms or impairments. And, so, after a three-week stay in the hospital, she was ready for intensive rehab at home.

We left the hospital with so many unanswered questions. Would this happen again? What is the impact on life expectancy? What preventative actions could we take? Despite all of the diagnostic data, we had very little insight into what was actually underlying her presentation. Fibromuscular dysplagia and segmental arterial mediolysis were two of the diagnostic labels we were given, but no one could find any research – not even a case study – that addressed her apparently unique medical presentation. As a result, we had virtually no information to calibrate our expectations for the future. A proverbial sword of Damocles held over our heads as we headed home.

#### WHITE

Throughout the horrors of the hospital stay, our friends, family and colleagues rallied around us – caring for our children, providing regular meals, helping with housekeeping, coordinating hospital visits, assisting with administrative leave and creating an incredible community of love and support. I tend to think of myself as a fairly private person – always a little reticent to share my inner life with larger groups of people. However, during this period, I found myself living out loud more than I ever had. Our friends had set up a group chat to keep folks apprised of my wife's health – the size of the group seemed to grow with each day she spent in the hospital, adding more and more people whom I really didn't know. Nonetheless, I provided a raw, play-by-play of the drama that we were living. At first, I framed it as a service for others, but slowly I realized that I needed this as much as anyone. Sharing the emerging findings as I received them, provided me with a sense of purpose outside of myself. It helped me feel like I wasn't alone and helped me gain insight into my own reactions. I can't think of a period in my adult life when I let so many people into my suffering, or when I was so dependent on their support to manage it. I look back at this time with so much awe and gratitude – I'm so proud of how everyone in my family navigated this experience and so thankful for the incredible support that we received from so many.

#### GREY

With my wife's transition back home, came my transition back to full-time work. In many ways, this was a more complicated time for me. I didn't know how to calibrate this new mode of living with my professional life. I would provide colleagues with frank details about my wife's health, then feel embarrassed when my disclosures weren't immediately validated. I would keep things in, then feel awkward when my colleagues didn't know about such a major life event. These tensions were at play during the 5<sup>th</sup> International Congress on Whole Person Care, held in Montreal last fall – my first in-person professional event following the stroke. I was part of the Congress organizing committee and a couple of days before it started, was asked whether

I could complete a short reading to set the stage for a plenary session. I can read aloud - sign me up!

At around 11pm the night before, I sat down to read the piece for the first time. My wife was sitting across from me in our living room. I opened the document, and my heart sank. The story held an uncanny parallel to my recent life – and it didn't have a happy ending. *How the hell am I going to read this in front of a group tomorrow?* I chatted about it with my wife and resolved to give it a try – *what's the worst that could happen?* I read the story through a couple of times – the final sentences were the most provocative, so I marked them with an asterisk and wrote "SLOW" in the margin. The next day I started out strong. *Ok, this is going well,* I thought to myself. Then I got to the final section. *Shit. I was stuck. I knew that if I said another word,* I would burst into tears. So, I just stopped – hoping I could keep everything together. I couldn't. The tears flowed. And then, flowed some more. Folks came to my side. But I brushed them off. With an unsteady voice I started to read the final sentences. The story was about a middle-aged woman who died from prolonged kidney failure. It was narrated by her widowed husband and culminates in him recounting how upset he was when his wife didn't tell him about her worsening condition while he was away on a work trip:

"I asked her why she hadn't told me about it, and she then asked me what I would have done if I had known. I said, 'Well, I would have come back [home].' 'But that's exactly what I didn't want you to do', she replied, 'I want you to continue with your life and go on with whatever you are doing, you must continue.'[1]

Despite my wife having now made a full recovery from her stroke, I still choke up as I transcribe these words. It's so easy to imagine her – if the proverbial sword ever drops – saying them to me, and how desperately I don't want to hear them.

#### **EMBRACING VULNERABILITY**

My personal growth seems to intertwine with discovering and socializing my ever-evolving vulnerabilities. This seems to come naturally within black and white contexts – when I'm feeling most confident and intentional about how I want to be with others. It's the grey that remains my greatest challenge – when I don't know what's best, when I'm caught off guard, when I lose control. And, yet, such experiences seem to also hold value – new insights into what makes me, me; new understanding of how I can open myself to others.

After my Congress reading, the hardest feeling to reconcile was not being able to explain myself to the audience – I desperately wanted to justify my tears to those who I didn't know. But, for those who *I did know* – *or was even just getting to know* – the experience seemed to bring us closer together, coaxing professional relationships from grey to white. With this progressive opening, also came unexpected gifts. For instance, joy. I could have never guessed just how many moments I would come to cherish during my wife's hospital stay – holding my three-year throughout the night to help her find comfort; seeing my kids embrace their mom during their first hospital reunion; laughing with hospital staff during light-hearted

moments; sneaking off from the hospital, with my wife in a wheelchair, to savour some sunshine in a nearby park. In retrospect, opening my suffering to others, seems to be a key to its transcendence.

I'm also learning just how much I value helping to foster avenues and spaces for others to express and share their vulnerability. One of my closest colleagues was recently diagnosed with advanced stage cancer. Like me, she has two kids under nine. Similar to my wife, the diagnosis came with zero warning. I cherish the time we get to spend together. I'm surprised by how comfortable I feel, how much laughter we share and how much these moments mean to me. I don't think such positive feelings would have been possible without having navigated my own recent hardships. Similarly, the articles in this issue courageously translate diverse experiences of suffering into something life giving. There is an uncanny power in the spaces that foster this type of sharing. I hope you take time to read and reflect upon each of them, and that they help you explore new, unexpected ways of opening yourself to others.

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#### **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 has been serving as Editor-in-Chief since 2023.

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# STORYLINES WITH AN OPEN PALM

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KEYWORDS: Vulnerability, Fear

or the past several weeks, I have struggled to write about fear and vulnerability. Every time I would squeeze out sentences, they veered into abstract concepts or impersonal generalities. The result was a narrative that felt empty and unnatural. One night, during this frustrating struggle, I had a dream. With an open palm, I held out a dismantled Rubik's cube for a group of colleagues to see. "This is how I am." I told them. When I woke up, something about the dream felt right.

A few days later, I told my husband about the dream. Halfway through though, he interrupted me. "Wait a minute," he said, concerned, "a broken Rubik's cube is irreparable. It's something you can never fix or play with again. Are you saying that you're broken beyond repair?"

I was quiet. The quick answer is no, I do not think of myself that way.

The slow answer is not so simple. There are a few times when I have feared that I was irreparably damaged. The most obvious was when I received a professional complaint. I recall getting the letter from the mailbox, reading it in the living room and being flooded by utter shock, disbelief and fear. Right in the core of my desire to help and do good, there was an experience of harm. It was like an invisible earthquake, immediately undoing trust in myself. I started second-guessing decisions I made, even in areas where I did not doubt my skills. I started experiencing everything as burdensome and heavy, as the aftershocks of the complaint started permeating other aspects of my life.

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With the complaint, I was faced with what I have always diligently tried to avoid: harming others and making mistakes. The fear of harming others and making mistakes are two of my core vulnerabilities. They are the common thread in events that have threatened to dismantle me over the years. That is the image of the broken Rubik's cube I was displaying in my dream. It was an image of vulnerability and imperfection, not of irreparable brokenness.

But my dream was not only about my vulnerabilities per se. It was also about candidly admitting to them. I realized then, that in real life, I had been profoundly avoiding writing about my vulnerabilities. I preferred to close my hand on that Rubik's cube or hide it behind my back. But honestly admitting to them is precisely what had felt right about the dream. And that is why I decided to offer this article. Not as a story about a dream or a complaint, but as a gesture of admitting to fears and vulnerabilities with an open palm.

### **Biographical note**

Sandra Derghazarian is a community neurologist and a physician coach who has loved stories for as far back as she can remember. *Storylines* is a column in which she shares stories about work and life. As much as possible, she tries to stay loyal to the messy and sometimes contradictory experiences of everyday life.

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# **54-YEAR-OLD MALE—CHIEF OF PEDIATRIC SURGERY**

### **Sherif Emil**

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#### KEYWORDS: Vulnerability

t is a chillingly cold winter morning. I wake up at 7:00 AM, shower, put on some casual clothes, and head to my office at the hospital. It is still eerily quiet. The team has not arrived, and rounds have not started. I remove my wedding band and watch, and change into my scrubs – a routine I have carried out hundreds of times. But this is not just another day of surgical practice. It is a Saturday. I am not on call, and I have no cases pending. I will not be seeing any patients. I am here for an MRI – my sixth in four years – and I learned that it is much easier to change and leave everything in my office rather than to do the same at the MRI suite. Rewind the clock four years. As I approach the gastroenterology reception, I unfold the consult request given to me on discharge 72 hours earlier. I take a quick peek at the text as I hand it to the receptionist. It starts, "54-year-old male, chief of pediatric surgery....".

Nothing could have summarized my journey of the previous five days better, a pendulum swinging constantly between another 54-year-old male patient and my professional position as a pediatric surgeon. The dull epigastric pain had been intermittent for several days. It was not terrible, but something was different. I had never experienced such pain. I never suffered from dyspepsia, gastroesophageal reflux, or biliary colic. I worked through the pain, denying the distraction. After 48 hours, I mentioned it to my colleagues, seeking reassurance more than a diagnosis. No one seemed too concerned. That is all I needed to keep going.

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Seeing me quite uncomfortable in clinic the following day, my fellow asked, "Could you have pancreatitis?" "Why would I have pancreatitis?", I replied dismissively. I had just had an ultrasound a few months before for follow-up of two small gallbladder polyps, revealing no change and no stones. I drank sparingly, but I had been on a vegan diet, without alcohol, for the previous several weeks, observing Lent.

The pain continued. Like every bad doctor, I self-medicated, starting a proton pump inhibitor that my wife had used in the past. It did not help. So, I called a friend – two friends actually – pediatric gastroenterologists. I liked their advice. Proton pump inhibitors can take some time to kick in. I could use some antacids in the meantime. I did.

#### But the pain got worse.

Finally, just before midnight on a Thursday, the sixth day of symptoms, my denial started to crack. The epigastric pain was severe. I elicited definite tenderness on self percussion and palpation of my abdomen. Each breath was uncomfortable. I left my wife and daughters sleeping and drove myself to my own hospital – a children's hospital. I asked for an abdominal series. Good. No free air. Nothing impressive. I filled a requisition for some lab tests and asked one of our emergency room nurses for a favor. He drew them and I went to my office to wait. An hour later, the diagnosis was obvious. I had pancreatitis.

I printed a copy of my labs and walked around the corner to the adult emergency room. "I am a surgeon at the Children's and I have quite severe abdominal pain from pancreatitis", I said quite calmly. Perhaps too calmly. The ER clerk responded, "Sir, just have a seat. I am getting an ambulance right now." She did not seem to have heard what I said. Here we go – another 54-year-old male in a large busy urban emergency room. Luckily, the triage nurse across the hall approached me in a hurry. "Did I hear you say you're a surgeon and you have pancreatitis?" "Yes," I replied in a very matter of fact manner. "Come with me." From there, things seemed to move at lightening speed. ER room found. IV placed. Labs repeated. Morphine given. CT scan done. Having accompanied family members to the same ER before, where the trajectory of these steps was significantly slower, I realized that now I was in "chief of pediatric surgery" mode. I experienced a mix of guilt and relief.

Shortly after the CT scan, a junior surgical resident walked up to my bed, as I was finally starting to experience some narcotic-induced relief. He had rotated on my service less than a year before. "Dr. Emil, your CT shows pancreatitis and an IPMN." I am a pediatric surgeon. Pediatric pancreatic lesions are extremely rare. I last recertified in general surgery 10 years ago. For the first time in several hours, I swung back to the 54-year-old male. "IPMN – what is that?", I responded, shamefully revealing my ignorance to one of my junior trainees. "It stands for intraductal papillary mucinous neoplasm – we sometimes observe it", he answered in a somewhat nervous tone.

Pancreas? Neoplasm? Sometimes? After 28 years as a physician, I had promised myself never to be surprised if I was to be suddenly diagnosed with a grave illness or condition, no matter how serious. I had promised myself to never ask "why me?", but rather to ask "why not me?" Nevertheless, a streaming filmstrip

of images started to play in my head – my wife, my young daughters, my clinic tomorrow, my operating room next week, my trainees, my research, the book I had just completed against all odds over four years of continuous work, my mother who died of un-explained pancreatitis, my father who practiced medicine actively until two weeks before his death from a myeloproliferative disorder.

I interrupted the stream by uttering my go to prayer – the Jesus prayer – "Jesus Christ, son of the living God, have mercy upon me, a sinner." I uttered it repeatedly until I fell asleep.

I was awakened by a mild jolt to my bed. "I am taking you to your room," whispered a young patient care attendant. A miracle or the "chief of pediatric surgery"? I had expected a day or two in the ER before an inpatient bed could be found. Before dawn, two more residents examined me. I appreciated their need to appear thorough in their evaluation of the 54-year-old male with pancreatitis, but also noticed the cursory exam motivated by their discomfort evaluating the chief of pediatric surgery, one of their faculty.

As morning broke, I couldn't help but feel that my life had been severed in two parts by the scalpel of the diagnosis. Yesterday, I was chief of pediatric surgery. Today, I am a 54-year-old male with pancreatitis and a pancreatic neoplasm. During my 36-hour hospitalization, the first in my life, I would call for my own inpatient gastroenterology consult, ask my radiology friends to expedite an in-patient MRI, and insist on lowering my intravenous fluid infusion rate so I can decrease the frequency of my trips to the bathroom. But I would also experience the challenges of the hospital environment like any patient. I knew that, at the input of a few letters on a computer screen, I could read the latest literature on IPMN's but I did not have any desire to do so – for four weeks after my diagnosis. At every visit and consultation, I would wonder if I was receiving the 54-year-old male recommendation or the chief of pediatric surgery recommendation.

When you are the chief of pediatric surgery with a diagnosis that can dramatically change your life, you get advice – lots of advice from other doctors. "The Board answer is to get a Whipple." "Get the surgery while you are young." "You should stop your mission trips to Africa." "Get a fifth opinion." "See this person. He is the best." As the diagnosis settled in, I gradually resolved to flee from such advice. I resolved to continue to live my life as I have always lived it, until the day comes when I can no longer do that, whether in a week, a month, a year, or a decade. I continued my busy practice, my research, my teaching, my leadership position, and most importantly my overseas missions, which annually renewed my purpose, hope, and faith. When COVID hit and many panicked because of losing control, I was well ahead. I had already learned to live with little control of what came next, believing wholeheartedly that while I am not in control, God always is. And when I had a patient or family in shock about a diagnosis, I could look them in the eye and say "I understand. Not just because I have shared the journey of many like you. But because I have been there myself."

Four years, six MRI's, one CT scan, two PET scans, three endoscopic ultrasounds, and two biopsies later, I am still here. On this cold winter morning, I complete the MRI and return to my office. A few minutes later, I look at the images on my computer screen and measure my lesion. After four years of intermittent growth, it seems stable. I can continue as chief of pediatric surgery. As physicians, we understand the ingredients of healing – faith, family, friends, love, purpose, and caring physicians. As I continue my journey, I am certain the now 58-year-old male patient and the pediatric surgeon will occasionally clash, but they will also increasingly find common ground in this universal path of healing.

### **Biographical note**

Sherif Emil, MD, CM, FACS, FRCSC, FAAP is the Mirella and Lino Saputo Foundation Chair in Pediatric Surgical Education and Patient and Family-Centered Care in the Faculty of Medicine and Health Sciences, McGill University, Montreal, Canada. He is also the Associate Chair for Education in the Department of Pediatric Surgery, and Professor of Pediatric Surgery, Surgery, and Pediatrics at McGill University. He currently serves as the Pediatric Surgery Specialty Consultant for Mercy Ships International, and was recently awarded the 2024 Donald E. Meier Humanitarian Award by the American Pediatric Surgical Association. In addition to his academic work and publications, he enjoys writing and has published multiple pieces on a number of topics in the lay media.

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### **PHYSICIAN, HEAL THYSELF**

### **Megan Persson**

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**KEYWORDS**: Vulnerability, Crisis intervention, Self care, Family practice, Emergency Medicine, Mental Health

found the patient sitting on a stretcher between two walls that served as a temporary room. It was a busy night, and the sounds of raised voices and ringing alarms ebbed and waned throughout our conversation. I closed the curtain behind me in an attempt to give some visual privacy, even if it couldn't block out much of the noise, and sat down beside them. I apologized for the limitations of the circumstances, knowing that I couldn't completely keep the conversation we were about to have from being overheard by those nearby.

They looked great for their age. Although in their nineties, they stood upright, mobilized easily without aid, and appeared comfortable. They were mentally quick, and physically well. In spite of this, they were now a patient in the Emergency Department after admitting to someone in their senior's home that they felt that they had nothing to live for.

They didn't have a plan to take their life, but they felt very alone since their spouse died. They admitted that a number of physical symptoms took a toll, even though it was considered normal aging. Nothing was easy anymore, and they wished that "we could just go at the time of our choosing".

As they spoke, I reflected on other patients I had met who seemed more at peace with their situation in much worse states of health. What was the difference between the two? Was it a clear division between health and mental illness? Was it the circumstances of loss? Could it stem from personality traits or outlooks on life?

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International Journal of Whole Person Care Vol 11, No 2 (2024) When they finished their story, I laid out our options, and they agreed to speak to psychiatry voluntarily. The next steps were obvious. Treat their grief and depression, and they should feel better. I left to write the consult, and while I saw other patients, psychiatry decided that they needed admission. They prescribed talk therapy, and medication.

In the scope of my shift, this was a memorable patient interaction, but one among many. It was a familiar story, and my decisions were straight forward. Once the details of their case were settled and handed over to the admitting service, I didn't think about them again until later. I might not have remembered them if I wasn't reflecting after my shift, having parallel thoughts of my own.

I was healthy and comfortable. I had social activities and pastimes that kept me active and engaged. I had work that felt valuable, friends and family that I loved, and things to keep me busy for my lifetime and beyond. I didn't feel anxious or depressed. The trouble was that I had reached the same conclusion that my patient had voiced. I just didn't feel like I had anything to live for.

Delayed gratification has always made perfect sense to me. Discipline. Sacrifice. This is how I achieved many things I am proud of. It's how I did well as a student and got into medical school. It's how I worked 24-hour calls and got through 100-hour work weeks. It's how I trained and ran a marathon, how I paid off a mortgage, and how I save for retirement. It's how I got to be where I am today.

I have started work needing to pee, only realizing at the end of my shift that the need had only gotten more urgent. I have felt hungry at work, but not touched the food I had brought upstairs in my locker, prioritizing the long list of pressing tasks amidst the chaotic interruptions that challenged my leaving the department. Only after handover of patient responsibility to a colleague would I consider my physical needs, and take the time to eat my lunch, often at supper time. I see others around me doing the same. The human body and mind are resilient. This is what needs to be done, and I have done it before. Others do more or have it worse. I can use my time off to rest and recover. This is a marathon, not a sprint.

For years following divorce, I found myself either working or caregiving. Any free time was spent recovering. I was exhausted. My sleep was irregular thanks in part to shift work's disruptive pattern. When my schedule had a series of day shifts, my mood improved, but I often couldn't sleep through the night, and I never woke up refreshed. In my physician brain, this was still explainable by multiple causes; negative life events meet pre-menopause, and an undeniable feeling of burnout from work. I was increasingly struggling with recurrent binge eating in my free time.

Still, I felt grateful. I enjoyed being in nature and hanging out with friends. I had proven over years that I could survive for an indefinite period of time like this, and I was certain that I could continue to do the same. I was surviving, but I longed to thrive again. I engaged in psychotherapy to try and find a better way to live what was increasingly feeling like a chaotic work life. It became clear that I didn't have much control of taking care of my needs on shift. I did start to eat lunch as close to lunch as possible, justifying the time away from the needs of others with the analogy of fuel being needed for an engine. I concentrated on the control I had over the rest of my life after work. I ate when I had time and opportunity. I slept as much as possible.

I discovered that I had lost the ability to tell if I was hungry or full, tired from lack of sleep or fatigued for other reasons. I had such a narrow range of sensations that I couldn't even tell if I was happy or sad. I could no longer neglect my own body's sensations for the sake of everything and everyone else. I was consciously retraining myself to take notice of subtle changes that were important in acknowledging my mental, physical and social needs, as often as life allowed.

It took a weekend of reflection to lay it all out in my mind. Despite this self-care, on every shift that I worked, the needs of others were always greater than my own, until it had its cost on my mental and physical wellbeing. My state of mind mirrored my patient's, and it was reasonable to colleagues that they be admitted to hospital. I gave myself the same empathy and concern that I had given this patient.

I reached out to my family doctor's clinic and asked for an appointment. A few days later someone emailed to say that my doctor was not available, and asking why I needed the appointment. "Depression", I wrote, self-diagnosing, but it was obvious to me that it was true. I was called back, and given a twenty minute appointment at the end of the week with an available doctor.

I noted the time allotted, and reflected on how best to use it. I had interviewed enough patients to know exactly how to tell my story in the most succinct way. What a challenge for those who don't have the same experience and capacity to summarize with clarity and brevity. I considered potential outcomes to the conversation, and was open to start medications. I wondered whether or not this new doctor would be ready to do the same.

The interview was straightforward, and I surprised myself with tears while relaying the information with clinical focus. The physician responded with suggestions, clearly considering all the aspects of my mental state that I had relayed. As they wrote the prescription, I commented that I wasn't sure they would be comfortable to treat me so quickly since we just met. They shrugged their shoulders, smiling gently, and reframed the comment back to me. "I am sure you do that all the time in the Emergency Department".

I had to laugh at myself. It was true, but I had to acknowledge that I felt uncertain on how they would respond. In this quiet well-run office with ample light and closed doors, I was relieved to be met in a safe private space. Although the time was limited, it was enough.

There is an intimacy needed in medical interviews that can be elusive and the bond between doctors and patients can seem fragile. I do my best to honour these unguarded moments as a physician, and I am moved in learning how it feels to be on the other side of the equation.

Although the environments where these two interviews took place were very different, the needs and responses were similar. I suspect that my patient had the same concerns and hopes that I did as a patient. I wanted to feel I was listened to as I shared my truth. I wanted to be validated and wished for a plan to a better state of mind. I did not expect a guaranteed outcome, but it meant a lot to be understood and met with care. I hope that I met my patient's fears with reassurance, and that I too was *enough*, in their moment of need.

### **Biographical note**

Megan Persson is a family medicine trained emergency doctor, and teaches for the McGill University School of Medicine.

She spends significant amounts of time thinking, reading, listening, and writing about the health care system and its impact on patients and health care workers in the intersection between community and hospital known as the ER.

She is grateful to work where those who seek care and those who serve them come together every day to provide the safest, most equitable, and humane service possible amid challenging circumstances with incredible creativity, perseverance, generosity, intelligence, and humour.

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### FINANCIAL INCENTIVES AS AN UNEXPECTED PATH TO WHOLE PERSON CARE

### **Michelle Goetz**

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KEYWORDS: Person Centered Care, Buprenorphine, Shame, Vulnerability

ost of us who enter medicine do so with pure intentions of helping one another, of being of service to our fellow humans. Most of the time, this noble aim is achieved. However, in 2018, I sat in a buprenorphine waiver class with a simple, self-serving objective: I wanted to earn an additional financial stipend. I know, not terribly service minded – unbeknownst to me, I wouldn't remain in this rather callous disposition for long.

I listened to the clinical vignettes, the social determinants of health and holistic care required in treating those with substance use disorder. I started to see similarities with my palliative medicine practice, where there is an emphasis on whole person treatment and physical, spiritual and mental health all intersect.

I began to question the division of substance use disorder from other chronic progressive illnesses, such as COPD, CHF, diabetes, and even cancer. Similar to addiction and substance use disorder, living with any one of these diseases involves an ongoing, repeated cycle of exacerbation and, hopefully, stabilization. Opening myself up to really listen, to remain curious, to walk with patients on their journey, highlighted more similarities between *all* diseases, than differences. I began to see the necessity of putting my palliative care

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International Journal of Whole Person Care Vol 11, No 2 (2024) mantra, of holding the patient-physician relationship at the pinnacle of all that is said and done, into practice with this new patient population, as well.

A male in his mid-60s presented to clinic after stabilizing from inhaled substance abuse. He found me on the federal substance abuse and mental health website of buprenorphine providers. I approached with curiosity and our initial conversation went something like this.

#### When was the first use?

"As a teen on and off. At 13, I started drinking alcohol. My dad drank. It's what I knew. But one time, my dad had to bail me out of jail, and he told me 'stay at home and drink, if you're going to do it."

#### Did your family also use substances?

"Just my dad. I have two sisters and they did not use any substances. They died of cancer."

#### Were you trying to escape or medicate yourself with these substances?

"Not at first. Running around in a group, and that's what we did: drank hard, fought hard and drank again."

#### How did your use evolve to other substances?

"Somebody asked me to do something, and I did it. I was 27 when I started using cocaine. It was a social thing a few times a week. I had back surgeries. I was given narcotics. I would go from one doctor's office to the next. I used the pain meds mainly for pain, but also for getting high. I never used IV, just snorted."

What support do you have in your life now? Are you living in a safe place? "In 2015, my wife was murdered by her drug dealer. In 2018, my best friend died of lung cancer, and I live with his wife now. She has two rules to live there: no drug use and no overnight guests of the opposite sex."

Since leaving drug rehab, this patient had a sponsor within a dual-dependent alcohol anonymous (AA) program, with whom he speaks regularly. He attends AA meetings. He feels a purpose outside of himself to help keep up the house and yard for his deceased friend's wife.

#### – Then COVID –

Visits converted to video and telephone. We saw one another every couple of weeks. He attended AA meetings virtually. He engaged with his sponsor.

#### – Then trauma –

He fell and broke his femur. Surgery ensued, followed by physical therapy and rehab. I followed closely after hospital discharge and provided pain management with buprenorphine and support via virtual visits to the rehabilitation center.

However, this trauma had changed his life forever. Eight months later, he struggled to walk and was unable to navigate stairs or drive – making it nearly impossible for him to join his preferred, in-person AA meetings.

This patient was suffering. He began asking for more buprenorphine. I requested an in-person visit and urine drug screening. He presented to my office in a wheelchair and barely recognizable, with deep circles under his eyes, extremely prominent cheekbones, and a huge loss of muscle mass in all extremities. He hung his head. He couldn't look me in the eye.

"I've been using," he said. I allowed for silence. I nodded my head in affirmation and waited. Then he responded in anger. "I am an addict! This is what I do! I guess you're not going to see me anymore?

– Then space –

I took his hands in mine. My next words would be the most important in the trajectory of our patient-physician relationship.

"You are my patient, and you are struggling. When you are struggling, we walk more closely together. We see one another more often. We journey closely together until you find stability again. You have found space and ability to live a sober and thriving life, I believe you can do that again. We'll do this work together."

He sat, stunned. He looked-up, for the first time in the visit. Silence passed. And a whispered, "thank you" hung in the air.

This space allowed for his story to be told – he was visited "by an old friend" in the hospital. He purchased illicit Xanax while in the hospital. He continued to use benzodiazepines and opioids supplied by outside friends in addition to his treatment plans created by myself and orthopedic surgery. He shared the financial checks he was bouncing, the shame he was feeling and the overwhelming sense that he was alone. Until this visit.

We devised a plan for weekly in-person visits, more frequent urine testing, increased conversations with his AA sponsor and initiation in the local county's certified peer specialist program.

He found creative and meaningful ways to contribute to household chores and his family. He lived with purpose until his eventual death from a complicated, but expected, array of comorbidities, including pneumonia, kidney failure and protein calorie malnutrition. He had remained sober for the rest of his life.

As for my story, a financial incentive and an unexpected therapeutic relationship opened my heart and expanded my perspective, bringing me back to my *Why*?, and the deep honor I find in service.

#### **Biographical note**

Michelle Goetz is a palliative medicine physician, internist and addiction medicine specialist providing care in the multi-state Mercy healthcare system. She serves in Mercy leadership roles closely supporting primary care physicians in primary palliative skills, specifically around advance care planning. Michelle is inspired to share her passion for ensuring patients receive the right medicine at the right time and are empowered on their journeys with serious illness. She is married with three young daughters and loves hiking, running, and reading.

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# NOT WITH A BANG, BUT WITH LOVE AND GRATITUDE

### **Hilton Koppe**

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**KEYWORDS**: Physician burnout, Post Traumatic Stress Disorder, Vulnerability, Reflective writing, Healing

#### **IN THE 1990s**

was a thirty-year-old freshly minted family doctor working in a rural village of 800 people. I'd left my family and friends and colleagues in Sydney for the wide horizons of a life as a country doc. It was a spur of the moment decision. I'd stopped for a toilet break on a road trip. Got chatting with the woman in the ice cream shop. She told me that she had moved from the city and how much she enjoyed her new life. "Sounds great. You don't happen to know of a job for a doctor in town, do you?" I quipped. "Well, as a matter of fact, one of our doctors was killed in a car accident last week," was her response which changed the direction of my life.

Within a couple of months, I was the new doctor in town. I was different to my predecessor. I was younger. Less experienced. Male. The people I now cared for tried to help me adjust to my new environment. "Dr Carol didn't do it that way!" So, I learnt to pretend. I worked very hard at trying to be a good doctor. It was exhausting.

Sometimes the veneer of bravado was sufficient. Thankfully I didn't have to pretend when I saw the children of the village. They were happy to accept me as I was. They didn't mind that I wasn't Dr Carol. They only cared that I cared. Once their parents could see that their children were happy to come to see me, they relaxed a bit too. Word must have spread around town that the new doctor was okay. "My friend (or daughter or wife) said I should make an appointment to see you."

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I found myself being a bit more relaxed at work as I felt able to be myself rather than my idea of what a doctor should be. But offering cradle to grave medical care meant there were moments of uncertainty. "I wonder what a real doctor would do in this situation?"

Caring for Judy offered me an opportunity to learn from uncertainty. Judy and her husband Geoff were university academics. They were pre-internet tree-changers, having moved 800km from their sandstone institutions to live the good life. This risky move was prompted by Judy's diagnosis in her early forties of a rare slowly progressive kidney disease.

There were no kidney doctors in our area. Judy arranged appointments with her specialist in the city to coincide with her visits back to the university. Kidney medicine was my weakest area. Too many interactions between weird chemicals and complex pathways for my simple linear mind. Pretence was impossible for me.

Fortunately, Judy and Geoff had become experts. Their research skills were put to good use. When we found ourselves at a new juncture in Judy's journey, I'd often end up asking them "I'm not sure what we should do next. What do you think?" Or "I don't know what's going on here, would you like me to phone your specialist?"

We successfully negotiated this dance for years. Until the lightning bolt hit me.

My room at the clinic faced west. I was finishing up work one evening and was struck simultaneously by the beauty of the sunset outside the window and by a deeply disturbing thought. "As much as I love my work and I love my life here, I don't want to still be sitting in this room watching the sun set in 10 or 20 or 30 years' time."

A movie of this potential version of my life flashed through my mind. Followed by an urgent call to action, "I've gotta get out of here before it's too late." This urgent call to action surprised me. It was out of step with my normal considered approach to big decisions. But it wouldn't leave me alone. Even though I couldn't understand why I felt so strongly that I needed to get away, something inside me was speaking more forcefully than the more timid voice saying "You're risking everything for a whim? Why would you even consider doing such a thing?"

My wife and I bought a small 4x4 SUV and a camper trailer. We were going to do "The Lap"! The excitement of planning for our year traveling around Australia was tempered by having to say goodbye to my patients, people I'd got to know so well over the previous seven years. I wondered how something could feel so right and so wrong at the same time.

Judy and Geoff were in Sydney during this time of goodbyes. The super-efficient small-town grapevine got the news to them that I was leaving. A card arrived in the mail the day before we headed off.

#### Dear Hilton,

We both wanted to thank you for your care during our time together. We appreciated many things you did for us. But mostly we were grateful for your ability to say "I don't know" when you weren't sure what to do next. We've seen too many doctors over the years, and you have been the only one to be that honest with us. Thank you, thank you, thank you. We will miss you but are so happy that you are following your dream.

Judy and Geoff

#### **IN THE 2000s**

I was a freshly minted father in my early forties. Fatherhood tapped into a previously hidden well of love. The power of this love for my son and daughter spilled over into a love for all children. There were times when this love intruded into my rational doctor's mind. I found myself overly worrying about the children I cared for.

There is a saying in medical circles. "If a doctor treats their own family members, then their family will be either hopelessly overtreated or hopelessly undertreated." I hoped that my newfound love for all children was not clouding my medical judgement is a similar way.

After our daughter was born, I found myself again a new doctor in a new town. Like my grandparents and parents, we had moved towns to give our kids a better life. My inner battles to be accepted as the new doctor were not as vigorous this time. As a mid-career doctor, I had found an acceptable balance between professionalism and humanism. Or so I thought. Until I met Sandra.

Sandra had just returned to our small town after six months in the city with her daughter Tahlia who was being treated for leukaemia. Tahlia was four years old. The same age as our daughter.

When I first met Sandra, she told me how difficult her time had been in the city. All the fears she held for Tahlia. The effort in trying to balance keeping her safe while trusting the invasive and toxic treatment necessary to offer a cure. She lamented how little attention was paid to her personal needs as a mother of a critically ill child. I suspected that she felt it was okay to ask for help for herself, now that the initial treatment phase for Tahlia was over.

As I was offering Sandra my complete support – "I want this room to be a kind of sanctuary for you. A place where you can let your guard down. If you ever need to." – I was struck by an unexpected and most disturbing vision. I saw my daughter in Tahlia's position – fighting for her life. "Not my little girl," my mind silently screamed as I envisioned our daughter bald, bloated from steroids, barely recognisable, as I had seen many young children during treatment for leukaemia.

And I was no longer with Sandra. I was grieving for an imagined horror facing our daughter. I started to cry. To cry. In the middle of a conversation with a traumatised woman whom I had just offered safety and sanctuary. How could I let this happen?

Somehow, I managed to pull myself back together and we completed the visit. I imagined that I would never see Sandra again. That she would want to see a real doctor.

The following week, a card was waiting for me at the reception desk. It was from Sandra.

#### Dear Dr Hilton,

I have been thinking a lot about what happened when we met last week, and have been wondering if perhaps you might have been feeling shame or guilt about shedding some tears during our conversation. I guess there is something really complex about the cultural expectations of men and the roles of doctors in our society.... "A doctor should hold it together in front of their patients. Men shouldn't cry, they should be the strong ones otherwise they are weak". So being a male doc, you have a double whammy.

You saw me at my most vulnerable last week. You had courage in abundance when you showed me your vulnerability via your tears. You responded to my pain in a way that allowed me to instantly connect with you and really know I was safe in that room to tell you or say whatever I had to no matter how dark or sad it was. You brought to fruition the message that vulnerability is a strength (not a weakness as most of us have learned to believe) because if you had shut me off with the usual clinical distance that is very common in medical settings, I may not have connected with you. Little did you know, I was going out on a limb that day, reaching out to say, "I have just had 6 months of clinical, cold, very highly professional staff who never once acknowledged my fear or pain." I had all my fingers and toes crossed that you would respond to me as a human, acknowledging my struggle.

This is what your tears did, you needed no words. You connected with me as a human.

So Hilton, I do not write this to convince you that you need not question yourself but to give my perspective of what your tears symbolized for me.

I am blessed to now be able to call you "my doctor".

Sandra :)

#### **IN THE 2010s**

I was the freshly minted oldest doctor in town. The senior doctor in the clinic had just retired. My patients were growing older with me. Many of them had chronic complex medical conditions for which there was no cure and often little to I could offer to ease their suffering. I hoped that my presence may offer some relief.

More and more of my patients were dying. Not due to neglect on my behalf, but because it was their time. I had to work harder and harder to make sure that their ailments were managed as well as possible. To ease their suffering. And to keep them alive. I did not always succeed. It was exhausting.

The pressures started to take their toll on my own wellbeing. I developed chronic neck pain. My sleep, when I wasn't awake in pain, was infiltrated by dreams of my patients. I started to dread going to work. I had never been like this before.

I sought medical attention for myself and was blessed that my doctor had the courage to tell me what I knew deep down but didn't want to believe, "You're done Hilton! You've got PTSD. You need to have a break from work. I'll write you a doctor's note in case you need it when you speak to your practice manager."

This is to certify that, until further notice, Dr Hilton Koppe is unfit for duties as a general practitioner.

As I trudged from my doctor's office with sick note in hand, I wondered if I had become the embodiment of the protagonist in the final lines T.S. Eliot's poem, The Hollow Men: "*This is the way the world ends. Not with a bang but a whimper.*"

The diagnosis of PTSD was both a relief – "do I get to rest now?" – and a trauma – "if I can't be a doctor, then what am I?"

I was faced with a choice. A very important choice. Do I follow my wise doctor's advice, or do I soldier on in the way medicine encourages us to be impregnable and invincible?

I chose the road less travelled, and stopped working as a family doctor. This decision was accompanied by feelings of guilt and shame. Fortunately, I'd always had a parallel career in medical education, and I was able to retain some sense of work-related meaning by continuing my teaching roles.

There were other benefits from being a patient more than a doctor. My main job now was to get better. I walked more. I ate less. Our vegetable garden flourished. I became a pickling and preserving prince. And as if by magic, my neck pain gradually disappeared!

#### **IN THE 2020s**

As the trauma of my diagnosis subsided and the symptoms faded, I began exploring a persisting pestering question. "Why has this happened to me?"

I wondered if it might be due to something more than an accumulation of vicarious trauma from bearing witness to my patient's stories over so many years. Perhaps it was my personality – maybe the qualities which (hopefully) made me a good doctor also made me vulnerable to the impact of trauma. On bad days, I wondered if maybe I was just weak. On more insightful days, I questioned whether the experiences of my parents and grandparents and their urgent need to get away when lives were in danger may have contributed to a genetic predisposition to accumulated trauma.

To answer these questions, I turned to a strategy which had been helpful over the years when I was faced with other unanswered questions – reflective writing.

I wrote some new pieces trying to understand what had happened. I reviewed some of my previously written pieces. Could these pieces of the jigsaw be put together into a cohesive whole? As a book?

And so, *One Curious Doctor: A Memoir of Medicine, Migration and Mortality* was born. It was surprisingly successful. Publication was followed by requests for interviews on radio and podcasts. Emails of gratitude from former patients and many doctors appeared in my inbox.

Just last week, an unsigned card arrived.

#### Dear Hilton,

I was one of your family medicine residents about 10 years ago. So many aspects of your teaching have stayed with me. Mostly about trying to be true to myself in my work. I wanted to thank you for that.

I also wanted to thank you so much for your wonderful book. As with your teaching, your willingness to reveal your vulnerability was lifechanging for me. I thought I was the only doctor to experience the things you described so perfectly in your book. Especially the bits about having visions. They happen for me, mostly when I feel fully connected with my patients. It was like you found the words to express what I felt but couldn't explain. And never felt safe to share.

I am happy for you that you made the courageous decision to step away from a profession that you so clearly loved. While you may not be seeing patients anymore, you are definitely still healing others.

With love and gratitude

#### **Biographical note**

Hilton Koppe is a writer, educator, podcaster and doctor living on Bundjalung Land on the east coast of Australia. He is a long-standing member of Dementia Training Australia's GP education team.

Hilton facilitates reflective writing workshops for doctors and other health professionals with the goal of deepening their compassion, overcoming professional isolation and reducing risk of burnout. The workshops have been adapted for people living with chronic and mental illnesses, as well as enthusiastic amateur writers. Hilton has been invited to present his workshops all the way from Byron Writers Festival to Harvard Medical School.

Hilton's book, <u>One Curious Doctor: A Memoir of Medicine, Migration and Mortality</u>, explores the personal impact of working as a country doctor. His play, *Enduring Witness*, is used to facilitate conversations about end-of-life care. Hilton is co-host of <u>Dementia In Practice</u>, a top 100 Great Australian Pod.

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### **VULNERABILITY IN PSYCHIATRY**

### Patricia Celan

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**KEYWORDS:** Communication in healthcare, Healing, Whole Person Care, Empathy, Personal reflection, Storytelling, Suffering, Trauma-informed care, Abuse, Psychiatry

don't trust you. Any of you." The teenaged patient said as tears rolled down her cheeks and she hung her head down, refusing to make eye contact. "I bet you don't believe me, and you don't understand."

We were in a conference room with her mental health team including the attending psychiatrist, a nurse, a social worker, a psychologist, and me, the psychiatry resident who was interviewing the young woman just 10 years younger than me. She had recently escaped a severely abusive situation prior to being admitted. Her post-traumatic stress symptoms were visible for all to see, and the entire team's hearts bled for her. We had often discussed her with pained concern given the severity of her background and her presentation, and we wondered how we could connect with her and make her feel safe, supported, and welcomed.

I have been interested in the mind since I was a child. People behaved in ways I didn't understand in my abusive home, and it frightened and confused me. In fact, a lot of people presented confusing emotions and behaviours even outside my home, and I made it my mission to understand by studying psychology as a precocious pre-teen. That helped me make sense of my life and the minds of the people around me, which led me down the path towards a career in psychiatry. The journey has been a rollercoaster, with gratifying moments of seeing my positive impact, along with the various struggles of working in a strained system with colleagues and authority figures who were sometimes very unkind to me. This journey has been full of grappling with the concept of vulnerability both personally and professionally.

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A dilemma I considered frequently was whether I could connect with this patient through self-disclosure. She felt so alone in her story of abuse, the unique horrors of her childhood shocking everyone else on the team, yet eerily familiar to me. It was almost like I had come face-to-face with a younger version of myself. Part of me wanted to disclose that we had similar childhood experiences, in an effort to get her to trust me so that I could help her.

I wanted to tell her that I had felt her fears, her anger, her shame, her inability to trust, her disgust with herself and with the world, her hatred of men paired with a vexing feeling of being inexplicably drawn to any older man who has a warm smile and seems gentle and nice on the surface. I wanted to tell her that I understood the choices she had made to survive in that home until she turned 18, because I made the same choices. Others didn't understand why she kept her secrets until she turned 18, but I did. When you're a teenager, unaware of the options the world has for you, the idea of leaving an abusive situation feels daunting, with fears of strange foster families or homelessness. The familiarity of abuse seems better by contrast. Those of us who have lived that life know that common theme of growing up too fast, developing enough maturity to take care of ourselves, but worrying that the world would cause us more harm if we tell anyone about the abuse while underaged. So, we keep our secrets until we are officially adults, and always wonder if that was the right thing to do.

There were so many moments where I wanted to tell her that not only do I believe her, but I've been her. Instead, I held back. Vulnerability in psychiatry involves authentic engagement with one's own emotions, while embracing the inherent risks of demonstrating such courage in attempting to create safe spaces for patients to feel understood and supported in their healing. I knew this, but still worried. Who knows how she would take my vulnerability? Would it be effective, or would it land wrong, the way my voice sometimes fails to portray the sincerity in my heart because my nerves create a monotone voice that makes me seem insincere? Would she even believe *me*? Would I be making it about myself if I told her we share similar stories? Would she feel annoyed, like I had stolen her spotlight? I struggled with the ethical and interpersonal dilemma of self-disclosure.

Between the bare, clinical walls of that hospital conference room, she shared a worry of her own. "I could become like him. A monster. I would rather die than be like him." She hid her face in her hands as she sobbed.

My heart broke for her. I could never judge a daughter by the sins of her father. Yet the same thoughts had percolated my own mind, as it did inside the minds of many children like us. How many times had I hated the blood coursing through my veins, because my father made a point of repeating "blood is thicker than water" every time he wanted to remind me to be grateful for my family when he was faced with my loathing after episodes of abuse? How many times had I wanted to empty my body of blood and be a corpse just to have nothing to do with him? How many times had I worried about what I could be capable of, with his genetics? Not the only woman in the family to be abused by him – but the only one with the curse of being related to him, my half-sister at least spared the shame of being half-monster as she and my mother

psychologically distanced themselves from our tormentor. *It ends with me.* I had told myself the day of my tubal ligation, a decision I had made to ensure that the evil would not proliferate through me.

What could I say to her to alleviate her worry when I shared her worry? How could I foster an environment of trust for her? How could I even expect her to trust me when I barely trusted anyone myself? I've seen some of the worst evils that humans can perpetrate. I've watched things that no child should ever have to see. I've known things about which I wish I could have remained blissfully, innocently ignorant. And it cemented me with a stubborn core belief – I can't trust anyone. This belief was reinforced every time I let my guard down and tried to trust someone, only to find myself betrayed again and again and again. Perhaps betrayal is the human condition.

While wondering how to get her to trust me, I also wondered - could I even trust this teenager with a selfdisclosure? Or would I then be judged for it? Would she use it against me later to hurt me? Would she make a formal complaint that I had been unprofessional by talking about myself? I wondered how to confront my insecurities while navigating the complex power dynamics and transference risks of a therapeutic relationship.

So I kept quiet instead, to maintain professionalism and hide my vulnerability.

I was not always self-aware about how vulnerable I could be in medicine, how much physicians can be surrounded by envy and hatred, how opportunistic anyone could be to take us down a notch if we seemed to be too successful or too happy. I did share my story with some people that I thought I could trust elements of it, at least. I shared my fear, guilt, and shame with mentors at work that I looked up to, who seemed to misjudge me, who I wanted so desperately to approve of me, like me, understand me. But I did not seem capable of building that desired connection with them. They became less my mentors and instead the judge and jury in punishment for oversharing. Everything I expressed about my feelings was too much for them, and I was blind to the inappropriateness of the context in which I practiced my vulnerability. Instead of understanding me and liking me, they seemed to misjudge me more strongly and slipped comments that demonstrated their growing disdain for me. They called me unprofessional for sharing the most secret parts of myself in my efforts to connect. They betrayed my trust and shared my communications with others. I was shamed by them for sharing, and I felt deeply ashamed of myself for laying bare the secrets that I had previously told no one. Most of all, I was embarrassed for being naïve enough to think I could trust the one who seemed to be different. Less a catalyst for personal and professional growth, and more a source of trauma, these experiences made the idea of vulnerability unsafe and later on made my own therapy journey difficult. How could I confront my own trauma and work through it, when I could trust nobody, battling an instinct to distrust even my blameless trauma therapist?

Connecting to my vulnerability with humility, aware of my fallibility, I still remained steadfast in my goal to support this young woman. How could I express the most important response to this young woman – an assurance that she is not a monster and will not be? How could I be sincere in that, instead of seemingly

just verbalizing platitudes and automated, robotic reassurances? How could I convince her that we don't need to become monsters just because of our abusive relatives? I felt that the answer was in taking a risk of being vulnerable with her. But how could I do that without overdoing it?

A thought slithered into my mind. We had more in common than just a history of abuse.

"You like reading Harry Potter, right?" I asked her. The teen nodded, her head still bent down as more tears fell. "I liked reading Harry Potter when I was growing up too. It's a nice escape when life gets too hard, isn't it?"

She quickly peered at me from the corner of her eyes, pondering me, then stubbornly turned her gaze back down to her lap.

I continued, "Remember that Harry had a little bit of Voldemort in him – the worst villain in the books had unintentionally put a piece of his soul inside Harry when he was a baby. That was why Harry had certain talents that connected him to Slytherin and Voldemort. That was why the Sorting Hat told him he could be great in Slytherin. But Harry told the Sorting Hat "not Slytherin". He chose to be placed into Gryffindor, and to be a hero rather than a villain. And every time he was faced with his dark side, his connection with Voldemort, he continued to choose to be good. You can choose that too, no matter the pieces of a villain you have inside of you. No matter our backgrounds, we all have the power to choose to not be a monster. I have faith that you will be a good person and you will help a lot of people."

She looked me square in the eyes. Her crying had stopped during my monologue, and we just looked at each other momentarily, quietly considering each other. As much as I wanted to tell her my life story, to present her with my survival guide for life, to tell her that it will get better, I felt that I could say nothing about myself. I had to keep it professional, because I didn't want to make it about me and I feared the consequences of disclosing to a patient.

Vulnerability isn't something to fear – it is something we need to embrace, as it can be a great strength. Humans connect most profoundly through sharing vulnerabilities. Yet having an open heart remains difficult, because too often our vulnerabilities can be misunderstood, shamed, or exploited. Sometimes it takes a little creativity to connect through vulnerability when we struggle with trust and when we are unsure if we have psychological safety in our environment. We may have a story to share, but we are not sure how much would be appropriate to share, and sometimes we feel that it is better to err on the side of caution.

Through our shared love of fantasy, this patient and I could discreetly forge an authentic connection on our most vulnerable secret, the challenge of wanting to die because of who we could be. The risk that terrifies anyone with a terrible parent that we could grow up to be terrible too. And the power we have to make a choice, to not be the victim or the villain, but to be the hero in our own story.

### **Biographical note**

Patricia Celan is a psychiatry resident at Dalhousie University. She completed her Bachelor of Arts in Psychology at Simon Fraser University and her Doctor of Medicine at the University of British Columbia. Patricia has a passion for trauma-informed care and her purpose in life is to become a trauma therapist, a dream which helps her to find meaning in her own experiences of adversity.

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### RITUAL

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#### KEYWORDS: Trauma-informed care

irst we prepare the terrain. Do you find speculum exams difficult? We can premedicate. Sometimes that helps. You have the power here. Say pause, or stop I will immediately obey. Immediately. I will say what I'm doing before I do it. I will sit you up so you can be above me, looking down I will check in with you verbally, and visually. Hand you the speculum to demystify. Here, move it around. Quack, guack. Every word carefully chosen. Let your knees fall to the side. (Never anything you've heard in trauma. Never say open your legs, I tell the residents) And if you tell me to stop, it's not a failure. It's a victory. You said no And it was respected.

It's a triumph. Be proud.

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### **Biographical note**

Before medicine, the author was a counsellor and intervention worker. She retains a keen interest in the social sciences and is forever curious about the human condition.

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# NARRATIVE MEDICINE: REIGNITING OUR SENSE OF PURPOSE AS CLINICIANS & PROTECTING AGAINST DEPERSONALIZATION AND BURNOUT

### Charlene Habibi

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Keywords: Physician burnout, Narrative Medicine, Reflection, Storytelling, Healing

ost western-trained medical students have encountered at least one PowerPoint slide early on in their training quoting Hippocrates, *Father of Medicine*, proclaiming that, "Where the art of medicine is loved, there is also love for humanity".

Often met with a deep sense of awe and pride, this sentiment serves as inspiration to trainees worldwide as they embark on the life-long process of strengthening the knowledge, attitude and skills needed for this work: that of healing. Medical students, staff and resident physicians enter this field, one of implicit personal sacrifice made in favor of countless hours spent studying in libraries or at the bedside caring for ailing patients, with the hope that it will have been worthwhile. It is thus rarely primarily financial prosperity, rank, or status that drive prospective applicants to this discipline, but rather the desire to selflessly help our fellow humans in times of vulnerability and need.[1] In this way, the practice of medicine is widely regarded as beyond that of a career or a vocation, but one of *calling*.

#### THE ONSET OF BURNOUT

Fast-forward a few years into residency or independent practice, and far too often little is left of this initial love for the art of medicine, let alone that for humanity. Hundreds, if not thousands, of sleepless nights later —sprinkled with unrelenting and, at times grueling, constructive feedback all whilst juggling emotionally

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charged, at times seemingly unappreciative patients struggling to navigate a complex and flawed healthcare system— and it is not unreasonable to see how the weight of these burdens can leave one feeling devalued and disconnected from their inciting motivating force.

The conditions in which medical learners have been conditioned to train and practice are wholly conducive to burnout, which the World Health Organization defines as an occupational phenomenon characterized by "feelings of energy depletion or exhaustion; increased mental distance [...] or feelings of negativism or cynicism related to one's job; and reduced professional efficacy."[2] Not only do those suffering from burnout bear the brunt of such effects, but so do those who are cared for by such affected individuals.

"Medicines cure diseases, but only doctors can cure patients," said Carl Jung. But what happens to physicians who are plagued with their own illness experience of burnout? Who is left to care for them or their patients? The statistics on burnout are clear and yet inconspicuously personified by afflicted physicians. According to the CMA (Canadian Medical Association) National Physician Health Surveys conducted in 2017 and 2021, nearly 1 in 3 physicians and residents experienced depression and burnout in their lifetime, with burnout rates having since doubled to an alarming 53% since the onset of the COVID-19 pandemic.[3,4] Suicide is a longstanding and well-documented occupational hazard amongst physicians when compared to their non-physician counterparts, where there is nearly a 40% and 50% increased risk of completed suicides among male and female physicians, respectively.[5]

Not only are patients navigating a broken healthcare system, so too are their physicians. A system established with unhealthy working conditions that for too long have gone unopposed and unquestioned. These grueling conventions have paved the path to generations of depersonalization and burnout: over 100-hour, high-stake work weeks, chronic sleep deprivation, vicarious traumatization, and compassion fatigue. As such, themes like building wellness, self-care, and resilience have started making the rounds into medical education. Training programs across the world have dabbled in yoga, meditation, and other mindfulness practices. The danger here, as world-renowned physician suicide expert Dr Pamela Wible warns, is that such wellness practices, though well-intentioned, tend to frame wellbeing as the individual's sole responsibility. This oversight adds another area of focus demanding the physician's time and attention, and absolves the responsibility of the system in which they train and practice.[6] Furthermore, with the still-present stigma surrounding mental health, especially among healthcare providers, there exists an added barrier of timely access, superimposed on the implications surrounding attaining hospital privileges, disability insurance, and advancements in one's career.[7]

#### NARRATIVE MEDICINE: HEALING OUR HEALERS

So, what of incorporating Narrative Medicine into our training programs? And what can be said about practices which encourage physicians to reconnect with their inciting passion and rekindle their purpose in service to others, notwithstanding the need for systemic reform?

In plain terms, Narrative Medicine is a relatively new model of practice, spearheaded by Harvard-trained general internist Dr Rita Charon, in which stories are recognized to be at the forefront of healing for both patients and practitioners alike. In *Narrative Medicine: Honoring the Stories of Illness*, Dr Charon describes it as "medicine practiced with [the] narrative skills of recognizing, absorbing, interpreting, and being moved by the stories of illness."[8] As such, this novel framework is posited to be able to transcend the inherently flawed system in which practitioners provide care, thereby being able to treat sick patients more wholistically and with fiercer intent. Moreover, this framework allows for those, physicians or otherwise, who provide care to the sick to be themselves, in turn, continually nourished.

The utility of narrative competence is not a new concept to centuries-old disciplines such as law, government, sociology, and education. These fields inherently recognize that stories are of vital importance in the search for truth and justice, understanding and appreciating human behaviour and relationships, as well as societal progress.[9] Moreover, these narratives provide a foundation in which to ground the worker in their daily undertakings.

Research has shown that it is often the element of emotional exhaustion that lends itself to adverse effects on one's work, relationships, mental and physical health.[10] Humans have the capacity to experience a myriad of emotions in a single day, at times multiple emotions at once, all from a single stimulus. Without interference, these emotional responses typically have a beginning, middle and end.[10] One might hear a crunching sound in the woods, feel a gush of fear, respond with fight, flight or freeze, and then realize that there was in fact no threat, or that it was successfully evaded. Eventually the surge of adrenaline subsides. And in such a situation, the response to the threat (either running away from or staying to fend off the threat) was the very one used to bring an end to the natural course of the inciting emotion. The danger of an otherwise adaptive fight-or-flight response lies in repeated exposure, in patterns that do not naturally include an end point, where the emotion lingers.[10] In psychology, this is often referred to as the "stress response cycle," which when unchecked, can contribute to burnout.[10] In medicine, physicians run from one threat to another, often without sufficient time to process their emotions, or to recharge.[11,12] Therein lies a unique occupational hazard for physicians in the helping profession, who are constantly surrounded by patients in need, and are without the knowledge, training, insight, time, or systemic support to find a way to end their cycles of stress.

"A scientifically competent medicine alone," Dr Charon proclaims, "cannot help a patient grapple with the loss of health and find meaning in illness and dying."[9] The argument can likewise be made that a strictly scientifically-minded and competent physician alone cannot grapple with the emotionally taxing demands of clinical and academic medicine. Instead, they are left to struggle to find meaning in the barrage of neverending patient care seamlessly lending itself to provider burnout. Narrative Medicine offers a remedy to, and protection from provider burnout, as well as an outlet to rekindle a collective sense of purpose as

disillusioned physicians strive to provide ailing patients with the best possible care with limited resources at their disposal.

#### **REFLECTION AS A CORE COMPETENCY**

Just as is taught the skills of interviewing, history taking and formulating differential diagnoses, so too must the skills of reflection be taught in the lifelong training of present and future physicians. Through reflection, and active creative expression —literary, visual, performance and sound— can physicians start to recognize and turn towards their emotions in order to gain the strength needed to reconnect with their calling, be present with their patients, and find the wellness from which is needed to tackle the unsustainable systemic perpetuators of moral injury.[13] The distinction between the stressor and the stress cannot be overstated. As Drs Nagoski plainly state in their publication on Burnout, "generally the strategies that deal with stressors have almost no relationship to the strategies that deal with the physiological reaction our bodies have to those stressors."[10]

For Dr Laura Vater, a practicing gastrointestinal oncologist, this turn towards narrative medicine, specifically in her practice as a writer, was almost instinctual. "I don't think that medical school prepared me for the emotions that I was going to experience in medical training," she starts in an interview with The Work Room podcast, "there's a lot of things that we witness: severe illness, death, grief, loss [...] but we don't talk about that."[14] She describes the experience which ultimately sparked her putting pen to paper. As a third-year medical student, pregnant and on an obstetrics and gynecology rotation, she had witnessed a woman — whose baby was at the same gestational age as hers— experience a stillbirth. "I remember [...] walking in the middle of the night [...] like I was no longer this student that was supposed to just stand there quietly with my arms behind my back and I just had this release of emotions. [...] that's when I really started journaling about my experiences in medical school. [...] That's what led me to writing. Taking those [journal entries] and shaping them into essays and sharing them with other people."[14] This narrative experience would go on to transform into her essay, *Papaya*, published in the Intima Journal of Narrative Medicine, which ends in the following:

"I had found myself in a place, in a career, where life gets upheaved, where death comes unannounced. It was an unnatural pattern of being. I was just learning how to weave such upheaval into the fabric of my life, and to go on living. I didn't know that learning how to navigate this landscape—to feel, to care, to grieve, and then restore myself again—was a skill as important as interpreting a blood count or stitching a suture.

When July came, with its sweltering days, so too did my daughter. She emerged with a piercing scream, with writhing limbs, with eyes wide open. The nurse placed her into my arms and said, "She's beautiful. Congratulations."

I would forever contrast the cries that night, and the coos, wails, and laughs in the months to come, with that silent room. That still-as-stone face. Those tiny feet. The ritual of loss. His death, and her fragile, flourishing life."[15]

Alongside her large social media presence, Dr Vater has since gone on to become a member of the Pegasus Physician Writers at Stanford and publish a number of other narrative medicine essays which can be found in the *Journal of General Internal Medicine* as well as *Blood and Thunder: Musing on the Art of Medicine*.

#### **OPERATING IN AN EVIDENCE BASED WORLD**

The evidence-based benefits of Narrative Medicine —though this area of research is still in its infancy can be found among literature published in the wake of the COVID-19 pandemic. In fact, just a few short months after WHO declared a Public Health Emergency, a perspective piece titled, *Storytelling and poetry in the time of coronavirus* by Barrett et al., was published. This piece explored various narrative medicine approaches in their pursuit to uncover how such avenues may provide solace and an outlet to healthcare providers during such a particularly tenuous time in healthcare. In reviewing various practical strategies utilizing poetry and storytelling, the practice of narrative medicine in such iterations as Schwartz Rounds and Balint groups are stressed to go beyond mere reflective practices and extracurricular pursuits. Rather, they have the potential to remind one of the strangeness of the human condition and lends itself to a sort of distance which, "invites space to recognize the shock of deviation from the norm as experienced in burnout."[16] In this way, it provides an "opportunity to stand back from [the] world, to contemplate it, before once again immersing ourselves in it, for better or for worse."[17]

One systematic review found that poetry, as a form of narrative medicine, may increase empathy.[18] However, the current body of evidence remains limited on whether there is a discernable reduction in professional burnout amongst physicians and other healthcare providers.[18] Of 401 screened abstracts, only 2 quantitative, 3 qualitative studies and 1 research letter addressed the relationship between narrative medicine and professional burnout. Only one quantitative study showed moderately reduced burnout post-intervention among high attendance participants, and one qualitative study noted limited reductions in burnout. As such, the integration of the humanities within medicine is currently lacking rigorous research and there is much unchartered territory.[18]

#### **RECLAIMING OUR HUMANITY THROUGH STORIES**

It is no coincidence that many published physician accounts, be they autobiographical or fictional in nature, often center around the loss and recovery of the physician's own humanity. Among such releases include Dr Paul Kalanithi's memoir, *When Breath Becomes Air*, published posthumously after succumbing to terminal cancer, as well as Dr Stephen Bergman's (pseudonym: Samuel Shem) world renowned satirical fiction, *The House of God*, detailing the dehumanizing experience of residency training. In fact, in a short

JAMA Network documentary, *The Making of the House of God*, it becomes clear that the author's primary intention in writing was to reclaim his sense of identity and process his own medical training. "Steve is a brilliant writer [...] and a lot of the humor comes from his recounting of the episodes," Dr Richard Anderson says of his colleague and former co-resident during the documentary, "But it is also true that gallows humour was the currency of our relationships, and it was the way that we coped. And we did need to cope to deal with our impotence in the face of human suffering."[19]

Dr James V. Lucey, professor of Psychiatry at Trinity College Dublin, at the MindReading Conference of 2017, speaks to the importance of finding a home in the written word for the countless patient stories encountered by physicians. In his keynote address, *Listening to Patients, Telling Their Stories*, he asserts that, despite vitally important confidentiality clauses, the "stories we hear are not secrets. They need to be told and sometimes the very thing patients want us to do is to retell them."[20] He reminds the audience of the cornerstones of medicine: inspection, palpation, percussion, and auscultation – or "to look, to feel, to tap, and to listen." He emphasizes the importance of listening to the history instead of relying solely on one's stethoscope, because "if you haven't got the story, before you even look at the biochemistry, you're really not going to get the answer."[20] He goes on to say that these stories need re-telling and that as physicians, this "storytelling is part of our being."[20]

In truth, the act of storytelling is not only an act of advocacy on behalf of the story's teller to increase visibility toward unique patient suffering, but also serves as an act of healing on behalf of the story's recipient. Penning out these stories, internalizing, engaging with and meditating on them — out loud, on paper; in music, movement, poetry or in prose connects us with who we are as physicians and as otherwise spiritual beings having a material experience. Likewise, Pediatrician Dr Rachel Naomi Remen warns her colleagues against relying solely on scientific objectivity in their practice, whilst attempting to protect themselves from the difficulties of this work. In her New York Times Bestseller, *Kitchen Table Wisdom: Stories that Heal*, she goes on to say that, "Objectivity is not whole. In the objective stance no one can draw on their own human strengths, no one can cry, or accept comfort, or find meaning, or pray. No one who is untouched by it can really understand the life around them either."[21]

#### CONCLUSION

Despite the years of extensive training undertaken by medical students and residents, or the decades of devoted clinical practice that follows, there remains much of human suffering that has yet to be fully understood or appreciated. Through the active practice of reflection and connection —of turning *to*, rather than turning *from*— can physicians begin to grapple with the unknown, that which cannot be explained of the patient or physician's lived experiences by the current body of evidence-based medicine. Such reflective skills must be fostered early on in training, encouraged in practice, and studied with the same level of devotion bestowed upon other facets of clinical teaching and learning. Narrative Medicine, as a nascent practice and practical tool in healthcare, offers tremendous promise in allowing the culture of medicine to

slowly transform into one that allows for objectivity and subjectivity to exist in harmony rather than in opposition. It creates space for the experiences and stories of patients and physicians to lend colour to the at times dreary concrete numbers, routine physical exam findings, and depersonalized radiographic reports in the path toward healing. In this way, Narrative Medicine provides a framework by which physicians can reconnect with their sense of purpose, process their emotions, and complete their cycles of stress, ultimately protecting themselves from the perils of emotional exhaustion and burnout.

For in the words of John Keating, portrayed by the late Robin Williams of Dead Poets Society:

"We don't read and write poetry because it's cute. We read and write poetry because we are members of the human race. And the human race is filled with passion. Medicine, law, business, engineering, these are noble pursuits, and necessary to sustain life. But poetry, beauty, romance, love, these are what we stay alive for. To quote from Whitman: 'O me, o life of the questions of these recurring, of the endless trains of the faithless, of cities filled with the foolish. What good amid these, O me, O life?' Answer: that you are here. That life exists, and identity. That the powerful play goes on, and you may contribute a verse. What will your verse be?"[22]

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