

## The black, white and grey of embracing vulnerability

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## EDITORIAL

# THE BLACK, WHITE AND GREY OF EMBRACING VULNERABILITY

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## BLACK

Last 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 dysplasia 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.■

## REFERENCES

1. Phillips D (ed). *Heroes. 100 Stories of Living with Kidney Failure*. Montreal: Grosvenor House Press Inc; 1998. p. 206.

## 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.