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Risk and Regulation at the Interface of Medicine and the Arts:

Dangerous Currents

Edited by

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Cambridge Scholars Publishing

Neville Chiavaroli: Through the Champagne Glass, or, what has Radical Arts to do with Medicine?

Has there been a more incongruous sight at a medical humanities conference? A crowd of delegates, holding their glasses of champagne duly supplied at the exhibition opening, congregate around a concrete courtyard at the back of the Dartington Hall estate, waiting and wondering who, or what, would emerge from under the white sheet covering the motionless human form lying on the ground. We bore witness to the following extraordinary performance.

The human figure stirred, removed the white sheet from itself, and sat up. We watched as the semi-naked young man commenced rubbing some form of liquid over his torso, every now and then glancing up at the assembled crowd with a quizzical look. We stared as he picked up a scalpel and began incising the skin on his chest, and we grimaced as the blood started to slowly trickle down his body, and as it became clear that he was carving the shape of his lungs on his skin.

Next, he lay on his back over a wedge-shaped mat, head down, and began slapping the front of his chest with his hands. His hands and chest became bloodier with each slap, until eventually he started coughing and spluttering, the unmistakable sound of phlegm rattling around his chest and throat. He sat bolt upright, and with a large intake of breath, coughed and spluttered and expectorated the mucous into one of the jars that had been prepared and placed beside the white sheet.

He closed the lid on the jar, turned over onto all fours, placed the jar in his mouth and, holding it there with his teeth, crawled slowly across the cracked concrete to place the jar at the edge of his space, just a few centimetres from the feet of the closest delegates. He turned around, crawled back to his wedge and sheet, and performed the same actions again. Each time beating his chest until the mucous was shaken loose, each time carrying the jar with his teeth to be placed next to the other jars.

When he had filled the final jar, the relief amongst the delegates was almost audible. But it was premature. Sitting on his heels, with the same quizzical half-smile he had given us at the beginning, he took one of the jars, twisted the lid open, held the jar upside down above his head, and waited – as we all waited, for an eternity it seemed – for the mucous to slowly creep down the inside of the jar, and stretch and finally fall into his open palm. Laying down the jar, he rubbed his hands together, and smeared the mucous through his hair. He then looked up at the assembled crowd of conference delegates, with a roguish smile and hair sticking out

at odd angles, and waited patiently until we realised the show was over, and that we needed to clap. He then stood up, collected his things, and sauntered down the lane at the back of Dartington Hall, giving one final breezy wave before rounding the corner.

We stood there for a several seconds, those of us who had stayed until the end, unsure of what we should do next, and for most of us I presume, what we should think. Sensibility had been a major theme of this conference. This performance had challenged our sensibility in one of the most confronting ways imaginable. One by one, people had turned away and walked to safer space, some bemused, some anguished. Those of us who stayed and watched, for the most part shuffled, squirmed, and suffered – yes, even if only vicariously – to the end.

We walked back to the Great Hall for dinner mostly speechless, save for the odd throw-away line to save face and perhaps more importantly, to convince ourselves and our colleagues that to witness such a performance, to allow it to proceed unimpeded and unprotested through to the end, was an act of respect and honour rather than of voyeurism, diffidence or insensibility. But forget sensibility; what most of us wanted to know I suspect was what sense was there in what had just transpired? And what did it have to do with teaching or practicing as health professionals?

These were the questions I was struggling with for the rest of the conference, and days and weeks later. And while the following attempt to interpret and construct a meaning for the performance may not be how the performer, Martin O'Brien – artist, academic, and sufferer of cystic fibrosis – intended it, it is a necessary act for this delegate, at least, who was simultaneously shocked, stimulated and discomfited by the performance.

Gradually through the performance, and in the days after, I imagined the artist's voice in my head:

You, healers, educators, fellow humans, do you want to know what it means to live with my condition? A condition that must be managed every day but can never be cured. That will shorten my days but god knows (because the doctors don't) by how much.

Ok. Well here are my lungs. Bloodied, carved into my skin so you can see them more clearly than any medical imaging will ever reveal to you.

Here is what I must do to live, every day, 4-5 times a day. Smack my chest. Loosen the deadly sputum. Cough and splutter it out. Do it again. Over and over and over again. Every day.

It hurts. It's tedious. It's a ritual that you've taught me to do. But you get to go home. This is what I do. Every day.

And every day I fill these jars with this slimy, stringy, sticky stuff you call phlegm or mucous. It could kill me, yet it's part of me. It looks like hair gel. Look, I'll show you. You gotta have some fun sometimes…

As a practicing physiotherapist, I treated many patients with 'CF'. I knew the facts about the disease, and I was a competent practitioner. I helped regulate their lives with such rituals of treatment. I had learned to utilise my empathy to understand and feel with my patients. I believe I understood what it must be like to have to live with the disease.

I realised after Martin's performance that I truly had no idea.

There can be no 'knowing' of the patient's reality through factual knowledge, nor through the emotional imagination of empathy, and certainly not in the highly regulated environment of clinical practice. Not through words, texts, or even the blunt images of medical textbooks, or at least not through these means alone. Theories of performance talk about 'epiphanic' knowing, the 'flash' of understanding that can come from the combination of narrative and kinaesthetic elements in 'irreducible experiences' such as live performance (Kohn, 2011). This form of knowing is the missing ingredient in an empirical, positivist training which most of us believe serves us so well, from a clinical outcomes perspective. The experiential way of knowing that such performances offer is our most effective path to perspective, deep understanding, and revelation.

What Martin and his fellow artists do is dangerous, clearly for them, but also for us as health practitioners. By breaking the rules and creating such risky situations, performance crashes through our regulated and de-sensitised perceptions of what it means to be a 'healer' and to be 'healed'. They reveal the otherwise unreachable reality of our patients' lives. And just as the pain and discomfort of daily self-percussion and mucous expectoration is necessary to hold the effects of disease at bay, so some moral pain and discomfort seems necessary for us as healers, to better understand the people we seek to heal, and embrace the humility the role demands of us.

It's a confronting message, one that jolts us out of our contented assumptions about what it means to be a competent practitioner, and a caring professional. While sipping on champagne, it is a particularly uncomfortable and unsettling message. But I am realising that that's why we need the arts in health care and education.

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