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Plenary address — A year of living 'dangerously': Reflections on risk, trust, trauma and change

Joyce Davidson

Department of Geography, Queen's University, Kingston, K7L 3N6 Canada

A R T I C L E I N F O

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A B S T R A C T

This paper examines the role of emotions in the construction and performance of mis/trustful relations; with medical professionals, their technologies, and ultimately, with oneself. Using personal experience of two common conditions as illustrative examples, it questions what it means and feels like to trust, and how, where and by whom such feelings can be enhanced or undermined. It explores some of the ways in which discourses of risk are mobilized and embodied to create a *crisis* of trust, asking; what kind of selves and emotionalities surface, and what are the health outcomes, when bodies are viewed as 'at risk'? Visualizing technologies that probe the interior for data play an increasingly prominent role in health-care, and are typically considered more trustworthy sources of knowledge about the body than anything that might be produced by the tech-free sensing self. However, not all (even 'physical') trauma can be seen or quantified, and not all information is equal. The paper reflects on the emotional dissonance that ensues when one's own perceptions and representations are at odds with those of medical experts for whom one is supposed to perform trust. It examines the feeling rules that are broken when we fail to appreciate our treatment at their hands, and asks: What happens when we resist expert author-ity by telling different stories about our embodied selves, ones that make space for emotions in contexts where they are rarely seen to count, and where only what can be measured matters?

Introduction

In this paper, I draw on personal experience of a couple of fairly common health conditions encountered during my 42nd year to try and think about the conceptualization and embodiment of risk, and to a greater extent, trust. In particular, I want to question what it means and what it feels like to trust, and in what ways — for example, why, and where, and by whom — those feelings of trust might be built upon, or broken to produce a *crisis* of trust, in oneself and/or one's health care providers. I'll look at the kind of selves that are produced and performed as a result of such processes, and the associated emotions and feelings (as in bodily sensations) that may, or may not, constitute trustworthy sources of knowledge about our health and wellbeing. How *do* our own perceptions hold up when pitched against alternative informants, especially medical professionals, aided by imaging and other technological sources of insight? Contemporary medical practice tends to diagnose and display health information in ways that digitize bodies, and this has potentially significant consequences for emotional life, especially if we ourselves look to and even rely on such measures of our own health and *worth*. The two concepts are so often closely associated, and in this paper, I worry about the implications of these connections and developments for selves as forever *fragile* achievements. I want to suggest that increasing clinical tendencies to rely on data and 'trust the numbers' over the nuances of our own insight have a disturbingly logical extension in the Quantified Self Movement that views selves simply as 'data emitting machines.'

In discussing my concerns, I'll be thinking through boundaries of various kinds, including those frequently placed between physical and emotional sources of trauma, and between visible and invisible health challenges and indicators. The distinctions between what can be seen and what can be felt can have profound implications for our experience and 'treatment', both clinically and culturally, and in my own case, can highlight discrepancies between theory and practice of emotional life.

I've used autobiographical methods a lot in the past to think about other people's emotional lives (e.g. Davidson and Smith, 2009). However, I've never drawn explicitly on my own experience in anything I've written before, and I hope that some of the

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E-mail address: joyce.davidson@queensu.ca.

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insights that emerge in what follows will have broader relevance for at least some of those working through emotional geographies, professionally as well as personally.

Event horizon #1: on being concussed

In attempts to write about what's happened over the last year, I've come to think of the significant moments in terms of ‘event horizons’, as involvements with something so massive, that no aspect of the life that surrounds the encounter can possibly escape its pull. The first point of no return came in the form of a concussion. It's a fairly pedestrian story – I wasn't engaging in any high-risk behaviour at the time – I just slipped, and lost consciousness, standing beside my car. It was just me and my daughter, January in Ontario, so minus 20 odd with wind-chill, and we live well out of town at a distance from potentially helpful neighbours. So I was out cold (pardon the pun) for I don't know how long, and came round to awareness of the world with my four year old asking, ‘why won't you get up?’ I spent more time than was healthy during the months of recovery that followed wondering what would have happened to her if I *hadn't* been able to get myself off the ground, but, in that moment, I thought I was okay, that I'd had a lucky escape. I wasn't even aware that I had lost consciousness, because however trustworthy we believe our own senses to be, it turns out they're not all that informative about an *absence* of input.

To know you've been gone, you need to be able to recognize some change in your surroundings to indicate the passage of time, or have testimony from an observer,[1] who's preferably more than four. Although I knew that I'd hit my head, hard, because it hurt like hell, and there was sound and light of a kind I'd never experienced before, I didn't recognize this as a sign that I'd lost touch with the world, and it was only later that others' questions brought the discontinuity to light, between my daughter's playing in a mound of snow before I went down, and being right by my side what seemed like a split second later.

When I picked myself up, I felt a bit thrown, but I couldn't really see a problem with driving in for my intro-geography lecture. I called a friend for reassurance that I wasn't about to do anything crazy, but clearly, I was, and she was fairly persuasive about the need to get back into the house and cancel the lecture. My partner came home and took me to the hospital, which I thought was probably a waste of time, and it felt like the doctor thought so too. The examination was very brief. He checked for lumps and signs of bleeding, and did a few quick tests of cognitive function and eye movement, before saying I was fine, but should probably take the rest of the day off just in case. He said it wouldn't be a bad idea to avoid reading or watching television over the weekend – this happened on a Friday – but that I'd be good to go back to work as usual on Monday.

This seemed reasonable, because I felt okay, though maybe a bit detached; I remember being only mildly concerned when I found myself standing right behind a car that was obviously about to reverse out of the hospital car park. I was holding my daughter's hand, and though I'd seen the driver get into the car and there was only one way for it to go, it didn't occur to me that we should move out of his way. I didn't *feel* any danger, or even any real sense of alarm about the signs I'd failed to interpret, but kind of knew, intellectually, that enough was out of the ordinary here about how I was thinking and feeling to suggest that my partner should keep an extra eye on our daughter.

I did rest up for a couple of days, and felt like a bit of a slacker, so went back to work on Monday as recommended. The headaches were pretty bad, but just about manageable with over the counter pain meds, and although I knew I was more tired than usual, I had been given the all clear, so just started going to bed a bit earlier, and then earlier, and earlier.

For the next few weeks, I was aware that things were getting worse rather than better, and I was feeling overwhelmed, eventually doing very little beyond teaching my classes and going home to sleep until I had to get up and do the next one. I was having increasingly severe headaches too along with bone-crushing fatigue, and it was becoming unavoidably obvious that I had seriously reduced cognitive capacity. Which was a bit scary, to say the least. I started reducing the time I spent in front of the computer, because it hurt, and kept cutting back until I couldn't do 5 min worth of email without having to shut the curtains and crawl into bed. I was even struggling with hard copy readings for my grad class, and at this stage, had to start letting people know that I wasn't coping, and trying to come up with strategies to get me through the term.

I asked my doctor for a note to legitimize a request for help, mostly with the online aspects of a course with 350 students. Accommodations were never formalized, and I looked for support in other ways, arranging guest lectures, and asking for extra time for journal reviews and so on. I used the phone rather than email whenever possible, and got used to explaining that I wasn't feeling great, and might have to leave meetings early, then letting colleagues know that I might have to avoid eye contact in meetings, and eventually, keep my eyes closed completely, because I couldn't deal with the sensory input. I'd started having bouts of vertigo too, and *all* of my social and spatial interactions were seriously messed up.

The first doctor I saw after the initial hospital visit was sympathetic, but there was obviously nothing to see, and no offer of insight or follow up. I did go looking for help again, seeing different docs, sometimes in walk-in clinics when I was feeling desperate, and what was on offer were stronger painkillers. During one appointment I was told that I really *should* have recovered by now, and the fact that I hadn't suggested I must have suffered another concussion in the past. I supposed this was possible, maybe something that hadn't been noted as a child, but I didn't really think so, and it all contributed to the sense that I wasn't doing recovery quite right. In fact I kept getting it very wrong, staying in bed for a couple of days and thinking *this time* I'm all better, *finally*, only to find myself back where I started or worse, sometimes within minutes of beginning the performance of normality.

I made it through two and a half months in this way, with a daily dismantling of trust in my judgement about my ability to do or *be* anything – there was less and less of the social and spatial self-making stuff I was used to going on every day – and on the last day of the teaching term, I pretty much collapsed, finally getting a referral for a concussion specialist who ordered immediate, complete and indefinite medical leave, along with an MRI scan.

This was the first and only attempt to get beneath the surface in an attempt to see and measure the extent of this invisible disability; and I welcomed the intrusion. I was told, though, that concussion diagnoses were controversial. Scans were typically clear or inconclusive; when they didn't show anything, it meant that damage to the brain wasn't visible, not that it wasn't there, and where trauma was apparent, it wasn't always clear what it *meant*.[2] In any case, it

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[1] Niall Smith (2013) offers valuable insights into the disturbing necessity of witness testimony in another context, involving epileptic seizure.

[2] My own research hasn't provided a great deal of enlightenment about many aspects of concussion. Further, although there has been much talk in recent years of a ‘concussion crisis’ or ‘epidemic’ (Ventresca, 2014), I have found surprisingly little social science research on the subject beyond the context of sports injuries (e.g., McGannon et al., 2013).