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# WHOLE PERSON CARE

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#### **EDITORIAL**

# SOME REFLECTIONS ON WHOLE PERSON RESEARCH

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have been thinking lately about what it means to approach my research from a whole person perspective. To be honest, I don't really know. And, yet, I think I've been slowly and inadvertently cultivating this approach since I first started as a researcher, some 20 years ago. My sense is that it involves simultaneously comparing and honing two contrasting images. One is of the phenomenon itself. For me, this is people who are experiencing pain and suffering, but let's imagine for a moment this as the sun. It's hard to look at (and thus study) the sun directly, so a second, simplified image is needed. This is the *image* of the phenomenon that is generated through our research methodologies. This second image is always a distortion of the first. We might use a prism to help us study sunlight, but it can only provide narrow insight into the actual qualities of the sun. Extending this metaphor, I like to imagine my research tools as a crooked finger pointing at the moon. My job, then, is to try to straighten and reorient this finger so that it leads us toward the actual source of light we want to understand (rather than just directing us to the closest surface lit by its reflection).

Being able to see the distortion within the research-generated image requires an immersion in the phenomenon of interest. I want to cultivate a deep, personal connection with the phenomenon that I'm studying. My hope is to generate a set of memories, feelings or imagined feelings that can be conjured when critical reflection is needed. Einstein famously imagined himself riding on a beam of light, which, in

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turn, helped him see how the research tools of his time needed reorientation. For me, this often involves more modest means, such as self-reflection and careful observation of others. What exactly was I feeling when I broke my arm? Is my infant daughter suffering when she cries? What does my patient mean when they say they were blinded by the pain? In recent years, I've also started partnering with people living with pain in this process. Being able to integrate their first-hand reflections and observations within our research process brings us closer to our proverbial sun and dramatically improves the resolution with which we can examine the distortions created by our research methods.

Working to correct these distortions is an inherently messy process. Science loves parsimony. But when applied to the human condition, this can mean cutting clutter that often turns out to be essential. Tim Harford's book, *Messy*, provides a valuable compendium of historical examples that either embrace or shun messiness.[1] Harford uses these to effectively shine a bright light on the dark side of Occam's razor – essentially, bad things happen when we fail to embrace the messiness of the phenomenon that we're trying to understand. Consider the nature of pain for a moment. Unlike sight, sound and other human senses, pain is a jumbled mix of emotion and sensation. Pain's emotionality makes us jump to its attention – an inner drill sergeant that likely facilitated the survival of our species. Pain is also a function of who we are – our unique mix of genetics, learning history and present context make it so that we potentially each experience and interpret pain differently. Now, contrast this complexity with our most common clinical and research metric of the pain experience – a simple 0 to 10 scale of pain intensity. Intensity is certainly an important quality of pain, but it is still just one small part of this complex and subjective experience.

While not included in Harford's book, the failed *Pain as a Fifth Vital Sign* campaign provides a prime example of the perils of ignoring messiness within our research and practice.[2] The campaign, born in the mid 90's, was simple – let's try to improve pain management by integrating its assessment into the routine clinical evaluation of heart rate, blood pressure, temperature and respiratory rate. The pain intensity scale was advanced as the sole tool for administering this assessment. The problem, however, is that this scale fails to capture the meaning and context that shape patients' experiences of pain – 5 on 10 pain during labour and delivery can be quite a different experience from 5 on 10 pain during treatment for terminal cancer. The longer-term legacy of anchoring this international campaign to this overly simplistic assessment tool is, in part, today's opioid epidemic.[2]

Opioids turned out to be an excellent way of reducing scores on the pain intensity scale. But what these scores mean to the patient versus the prescribing physician might only be tangentially related. When the physician asks about pain intensity, the patient may also be communicating all of the suffering and hardship that they're currently experiencing — particularly if this number is their only avenue for conveying this distress, as it commonly was during the Fifth Vital Sign campaign. Patients' 11 on 10 pain scores are likely more often trying to convey suffering than they are trying to quantify their experience. Unfortunately, opioids

also provide an escape – that's all too brief, and far too costly – for this unaddressed suffering. In retrospect, this now abandoned "evidence-based" campaign to streamline and standardize pain assessment primed clinicians to ignore and mismanage the suffering that patients too often experience when in pain and turned out to be a tragically common pathway for addiction, overdose and death.

So, what is the whole person approach to research in this context? Well, for me, it involved a shift to using research methods that could engage with more of the inherent murkiness that characterizes human experiences of pain and suffering. Rather than trying to assign a number to everything I was studying, I started using qualitative methodologies that empowered participants to use their own words, via long-form interviews, to describe their experiences. I was blown away by what we found – an uncharted sea of data, just below the more superficial numbers that I had been focusing on. These qualitative interviews helped bring the whole person into better focus and allowed our team to develop a new richness for understanding the nature of pain-related suffering – findings that we hope will help inform more holistic approaches to its clinical assessment and management. Partnering with people living with pain in this process certainly added further complexity (or "messiness"), but also proved essential in helping us hone our interview approaches and interpret our findings. I was also surprised to learn how much I enjoyed running these interviews. It brought me closer yet to the lived experiences that I was trying to understand and made use of interpersonal communication skills that I had yet to fully engage within my research – having *more of myself* engaged in my work has been a reliable indicator of whether I'm headed to a place where I want to go.

And, yet, I don't want to advocate for a one-size-fits-all approach to whole person research. While qualitative methods are proving incredibly valuable at this present moment, I still don't see myself as a qualitative researcher, per se. My hunch is that less dogmatic entrenchment within our favourite research methods would better enable us to stick our heads up and build much needed connections to other research silos. In my work, I'm keen to explore how we might be able to link the qualitative themes on suffering that we're discovering to some of the more established brain-related changes that my quantitatively oriented field has focused on in recent decades. There's something appealing to me about exploring how this type of objective data might be connected to some of the messiest, most subjective aspects of pain. I also believe that fitting these types of disparate pieces together also brings us closer to creating a more accurate image from the research jigsaw that we're all trying to solve.

The more I reflect on this approach, the more I appreciate the unique role that practicing clinicians play within health research. Clinical practice is about as close to the sun as we can get, and it is an inherently messy process. We're confronted daily with the raw wholeness that is the person seeking help for their health. This vantage point offers unique insight into how our best evidence either serves or fails the patient in need. The first-person pieces in this issue capture this dynamic perspective beautifully. This issue also includes our first piece in the Journal's new *Wisdom in Practice* stream. The objective of this stream is to

provide a forum for clinicians to share how they've wrestled with aspects of patient care that don't fit neatly within evidence-based practice guidelines. The intention is to serve as an accessible bridge between our first-person narrative pieces and the more methods-focused research that is included in both this issue and the supplement to this issue; the supplement provides the abstracts for the work that was presented in the recent 5<sup>th</sup> Congress on Whole Person Care. My hope is that this Journal can help foster some meaningful community around this whole person research process – welcoming folks that might not see themselves as researchers into the scholarly art of trying to discern what shapes the orbit of our professional worlds.

#### REFERENCES

- 1. Harford T. Messy: The power of disorder to transform our lives. Riverhead Books; 2016.
- 2. Levy N, Sturgess J, Mills S. "Pain as the fifth vital sign" and dependence on the "numerical pain scale" is being abandoned in the US: Why? British Journal of Anesthesia. 2018;120(3):435-8.

# **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.