

Book review

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Lous Heshusius, *Inside Chronic Pain: An Intimate and Critical Account*,
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Despite its morbid subject matter, there are ways to turn illness narratives into compelling reads. One can ratchet up the drama and suspense (e.g. Frigyes Karinthy's *A Journey Round My Skull* and Jill Bolte Taylor's *My Stroke of Insight*). One can fill the narrative with deep insights (Oliver Sacks's, *A Leg to Stand On* and Arthur Frank's *At the Will of the Body*). Or one can aim for the lyrical brilliance of poetry (Anatole Broyard, *Intoxicated by My Illness* and Sarah Manguso, *Two Kinds of Decay*). In her new book, *Inside Chronic Pain: An Intimate and Critical Account*, however, Lous Heshusius chooses none of these strategies. Unlike Tennessee William's Blanche Dubois, she will have neither romance nor magic; she wants to tell it like it is.

A courageous tack, clearly, since the reality is downright un compelling and ugly. In a moment of inattention, the Dutch-born education professor now living in Canada was blindsided by another car as she pulled away from a stop sign. In that moment she exits a rewarding life, professionally and personally, and enters what she imagines to be 'Hell': constant, often paralyzing pain; endless visits to doctors and other health care providers (over 60 in all) who offer few answers and at times make the pain worse; and increasing loneliness as her world retracts inward and she becomes progressively isolated from friends and family. This new life has lasted 11 years so far, she tells us in her memoir, and is still going.

The living-hell of chronic pain is not something anyone would willingly choose to enter, even perhaps vicariously as a reader. It corresponds to what Arthur Frank (1995) termed a chaos narrative of illness. As opposed to the more comforting restitution narratives, such tales offer no happy endings or redemption, only darkness and stasis, a life resistant to meaning that will never get better. No wonder that others prefer to keep their distance. At a dinner party while Heshusius experiences a flaring of pain and could barely hold herself upright, everyone pretends nothing is wrong, even Heshusius herself: 'We all took part in excluding me.' The reality is just too painful to acknowledge.

And yet this is precisely why Heshusius's book is so important. I used to think it was just doctors who turned their backs on patients they could no longer 'help'. But the problem is much bigger, involving society as a whole, particularly in the West. As Susan Sontag (1978) noted a generation ago, the healthy will do everything they can to keep

‘the night side’ of life at bay. We are so obsessed with youth, health, and progress that we have no time for (or interest in) age, illness, and death. Yet for those who can’t escape the night side’s hellish precincts, the prevailing mindset is toxic.

Pain by its very nature is a subjective, private affair. It’s difficult to think about, let alone communicate to others because its content is imperceptible and elusive. As such, it emphasizes the separateness between people (Biro, 2010). The problem becomes even worse, however, for patients like Heshusius in which there is no visible wound or lesion on a CAT scan. Now the issue is not merely one of unsharability (which is bad enough) but also unbelievability. How can someone possibly be in such severe pain when there is no tissue damage, no reason for it?

The result is an echoing chamber of pain. Doctors, all but a few pain specialists, don’t have adequate training and experience, as Dr Scott Fishman notes in his excellent clinical commentary at the end of the book. When their materialist paradigm is turned on its head (pain without a physical source or without a fixable source), doctors are stymied and tend to prescribe medication indiscriminately or refer patients somewhere else, prolonging the endless cycle of suffering. Colleagues, friends, and family members, they too are often ill-equipped and skeptical. And even when they try to understand, their imaginative powers typically come up short – ‘What do you do all day?’ is a question that Heshusius is asked over and over again.

Inevitably, the need to turn away is felt by the sufferer herself. Looking at an old photo one day, Heshusius is filled with grief: ‘I like this woman. I want to be her. How did she slip through my feelings?’ (p. 26) For many chronic pain patients like Heshusius, the alienation from others and from oneself, coupled with the belief that the pain will last forever, leads to a desire to end life – ‘How often have I wished I could lie down and simply die.’ (p. 3) Heshusius cites a recent article in the medical literature showing that among chronic illnesses, chronic pain is the second major cause of suicide after bipolar disorder, and ahead of depression and psychotic disorders.

Thankfully Heshusius doesn’t take this route and manages to find some measure of relief from pain which she desires to share with others. She urges her fellow sufferers to take an active role in their well-being – by not accepting what a doctor tells you, by willing you to keep changing doctors until you find the right one, and by doing your own research even when it leads down unconventional routes. This approach led Heshusius to prolotherapy, which though far from a cure, and certainly not a universal one, has helped her considerably. In addition, chronic pain patients often can no longer count on the old ways of finding pleasure and hope; since the past is gone and the future bleak, they must focus more on the present:

‘here’ is the only place where I can really be. ‘This is it.’ Only this. Now. This pain above my left eye. This thought. This fear. The beauty of the music. The softness of this fur purring against me. The steel in my neck. This lying awake. (p. 39)

Finally, in a world that makes no sense, patients must learn to create some sense and purpose for themselves. Heshusius does this by writing down her thoughts and later formalizing them in a story – a story that will hopefully contribute to the eventual lessening of pain as it reaches out to other sufferers (*you are not alone*) and informs the

healthy (*this is what we do all day and your ignorance and neglect makes our existence all the more intolerable*).

The Mayday Fund recently reported that there are now 70 million chronic pain patients living in the United States. Yet despite the alarming number, these sufferers and their disease are almost as invisible as their pain: in the genre of illness narratives, in medical school curricula, and in research funding. Let's hope Heshusius's courageous and empowering voice helps change that.

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