



Volume 14
Issue 2

Guest Editorial

Being Seen, Being Heard: Health, Arts, and the Unspeakable in Lived Experience

For as much as a biomedical worldview and the organization of knowledge have generated incredible advances and innovations in health—lives lived longer, an end to the spectacle of certain infections or cancers being uniformly fatal—there is nonetheless an “epistemological narrowing” (Squier, 2007, p. 334) within this worldview. No longer simply a matter of controlling death and disease, adopting the centrality of a biomedical frame transforms life itself (Rose, 2001; Squier, 2007). But what gets left behind from this transformation? What aspects of experience hang in the spaces between the lab tests, imaging studies, transplants, and biologic therapies? What meanings are not conveyed, *what is not spoken*, in the language of medicine?

The health humanities are one place we might turn to when what we struggle with cannot be easily reduced to signal cascades; cannot be localized to particular regions or networks; cannot be modelled by the linearity, logic, or locutions of biomedical ways of knowing. In this issue of *Ars Medica*, we explore the notion of the “unspeakable” within lived experience: the lived experience of mental distress, the lived experience of neurologic difference, of cancer, of pain. Each piece in this issue

presents experiences that overwhelm our ability to order, describe, or categorize them (ordering, describing, and categorizing being foundational elements of a biomedical understanding). What we have are partial truths, truths in the telling, multiplicity in realities: lived experiences that are “uncontainable by words” (Hodgman, 2001).

What are the stakes, when we consider what it means for experience to be unspeakable? As Joshua St. Pierre (2015) writes, normative performances of oral speech communication are the *sine qua non* of rational human subjectivity, universalizing communicative purity, autonomy, and self-mastery. Insofar as speech communication is seen to be an initiation and marker of what it means to be human, non-normative and disabled voices are frequently excluded from communicative connection and the privileges of full social participation (St. Pierre, 2015). As you explore the pieces in this issue, hold in mind how this critique applies to what it means to speak and be heard in biomedical spaces: the expectations of narrative coherence and structure simultaneously render *unspeakable* certain aspects of distress and suffering, while marking the individual whose telling goes unspoken as Other. The pieces in this issue offer, in their own language, testimony of how normative communication can exacerbate isolation, loss, and grief. They gesture toward the failure of narrativity in biomedicine to capture the nuances, ambivalences, and tensions that are part of the lived experience of health and illness (to whatever degree health and illness can be made distinct).

This issue of *Ars Medica* opens with a special feature on lived experience in psychosis. The journal's special feature pieces are the creative result of a pilot knowledge translation project that took place between February and May 2019 as part of a larger ethnographic study of first episode psychosis in Toronto, Canada. The three feature pieces—visual arts-based explorations of the meaning and phenomenology of psychosis that emerged in conversation and artistic practice between researchers and participants—look to the ways in which multi-sensory modes of expression are needed to convey the unspeakable in psychosis. While the larger ethnographic project followed narratives of the lived experience of psychosis, tracing these against conventional biological narratives from within mental health settings, the move to an arts-based exploration of lived experience stemmed from the observation that much of the experience of psychosis could not be narrated. Themes of confusion, perplexity, disorientation, and isolation mark each of the special feature pieces and are given voice through form and colour, along with text.

In “Prose in Views,” we see seven multimedia pieces: poetry set to a range of visual images. In one, a texture of green folds. In another, a block full of black-and-white toilets. A third piece shows repeated horizontal lines. Within the series, repeated signs suggest an emphasis on getting through—an effort to affect another's consciousness by dint of plain repetition. The backgrounds of Moncef Mounir's poem-images are sometimes delicate, sometimes glaring: perhaps a show of am-

bivalence about communicating? Whereas “word pictures” are verbal attempts to convey a rich description of a visual scene, several of the poem backgrounds feature a repeating pattern of words—DOGMA, GLORY, MADNESS—a kind of picture made of words that echo over and over, producing a sense of flatness in the viewer, akin to the effect of repeating a word so many times it loses all meaning. The artist might be saying, “If I tell you something, the same thing, often enough, you will hear it but you won’t understand.” We are drawn in and kept at a distance. In an effort to express something about psychosis and addiction, the artist both articulates and overwhelms, possibly manifesting a wish both to communicate and to protect his private experience.

Sarah Traore’s “From Chaos to Oneness” offers us a wrenching recovery prose, and in a paired visual piece, a striking image of a brain. Her prose names psychosis first through terms of destruction: fire and ash, despair, shattering, and death. And yet her words mark also that there is life and creation within that excruciating experience. Healing was/is a transformation. In her image, we see an isolated, divided brain surrounded by schools of green and yellow marks and two blue question marks. We can guess her wish to explain, to describe parts or effects, such as the tensions between creativity, energy, and electricity on the one hand, and the questioning process she names as her recovery on the other. But we also notice the isolation of one hemisphere from the other, and wonder about *what* this brain is saying (or what is

being said to it) with its associated squiggles and marks. Is the isolation only that of the past, experienced during the experience of illness, or does it remain in some way? Healthy looking, in three beautifully rendered shades of pink, this brain is alone on the page except for its exclamations. Who will hear it? Who will understand it? There are not any words to help us relate more surely. When we do turn to the words of her prose, the pairing emphasizes the tensions that exist within the transformation she articulates.

katelynn's unnamed scribble shows concentric coloured whorls, repeated lines round and round, as if to lasso a middle part, where tighter white and red and black gestures overlap. Unlike the two previous artists, katelynn leaves out any clear reference and presents us with abstraction. Her image begins with the choice of black paper and ends with a final black knot. Bodily movement becomes visible; her gestures in drawing the lines give us a sense of energy that is in the end bound up on itself. Is the picture about health or illness? It seems to express the cohabitation of states: order and messiness, bright and dark, inner and outer. We cannot read it clearly, but we can know the feeling of moving quickly, repeated rhythms, and deep uncertainty.

Accompanying pieces in this issue offer a range of other aspects of lived experience and attempts to narrate and navigate the norms and expectations of biomedicine. In "Have You Heard of MS?" the prose draws us in to the perplexing, disorienting experience of a diagnosis (or not) of multiple

sclerosis: the clinical worldview attempting to order a collection of bodied disruptions and telling a partial truth through EMGs and MRIs. What happens when the truth of *that* telling overshadows a different, bodied truth? As Kristyn Kantenwein asks, who sees the loss, the isolation, the scars that form within the grip of the clinical gaze? Jane Schapiro poses a similar question. Speaking to the practice of mindfulness meditation, she asks us to contrast anguish rendered literate through clipboards, with its visceral reality, its history within a bodied life. Sophia Wilson's "Black Snack" gives us yet another kind of visceral sense, in this case of objectification and the loss of control that comes from medical procedures and the psychic impact of clinical gaze. Her use of the second person ("You sit up, fumble for dignity ... ") creates a distancing from one's own experience, while the poignant words drive home the distress and pain of objectification within the gaze as the you of the piece becomes an irrelevant, fungible, bodied vehicle for what matters—gut-cargo. In yet a different way (one that resonates with the multimedia poetry of Moncef Mounir), Amy Conwell's poetry brings to bear the visceral nature of experience. The pacing, alliterations, form, and content of these pieces pound with intensity and bring the reader into Conwell's world.

"Doesn't Work like It Used To" and "Making Plans" both take the reader into the depths of routine suffering that caregivers and family members also struggle with in the context of serious illness. In "Doesn't Work like it Used To," Casey Aimer

draws on the symbolic representations of the bureaucratic business of medicine—another clipboard, another form—gagging those who struggle through the system. When words do not work like they used to, we are left to cry without tears, to mark time through the machinations of medicine. The question remains, how are we to live in the visceral present, when that present includes the constant spectre of death? Gabriella Savarese asks this same question, ending with a note of hope and of resilience about the ability to make meaning of a life, no matter how long or short.

Themes of transformation carry across various pieces in this issue, from the special features to Kay Cosgrove's "Like the Ancient Magicians." Here we have a glimpse—fleeting—of transformation, the repetition of words drawing attention to the challenges of remembering and forgetting in the face of illness and death. Brian Volck's "Three Poems" also draw on the place of remembering, while foregrounding the fundamental question of how we might live *into* the brokenness of illness and suffering. In one, his plea, "help me," points us to the centrality of interdependency that is rendered palpable and visible through the experience of suffering and disability. If the normative locutions of oral speech we receive within a biomedical worldview are a manifestation of self-mastery, autonomy, and individualism, the poetics of illness drive home our deep relationality.

Adriano Mollica's "for Galen," a poem written by a senior medical student reflecting on the experience of anatomical dissection, provides a point of contrast. What this speaks to is a different kind of lived experi-

ence—that of entering into a biomedical worldview, a culture shift/culture shock, where a particular language, identity, and ontology is gained. But at what cost? Mollica begins with an imaginative stream of consciousness, considering the person whose body is being exposed and explored within the laboratory environment, but ends with the rhetorical question, “Who am I to think about what your life might have been like?” This is prompted by the demands of the biomedical worldview, for example, learning the Circle of Willis. When the weight of the universe becomes routine, who is the “I” left holding it? Questions of identity, of loss, of disorientation cut across the experiences of patient as well as physician, but they so often remain unspoken.

All of the pieces in this issue speak to the challenges of reconfiguring what one knows, and who one is, in light of illness, distress, and suffering. Many (particularly the special features) identify the uncertainty of futurity, contrasting what it is like to live in recovery, with the future envisioned within the normativity of a biomedical frame, and the cost of participating in this frame in order to achieve relief from suffering. Artistic modes—non-linear language, visual shape—help to overcome the challenges of articulation in these experiences, especially insofar as they open up new conditions of possibility for understanding. These new possibilities make room that did not previously exist within conventional framings or narratives of pain, neurologic difference, disability, or mental distress. As a whole, the pieces also speak to the ways in which being churned through a medical system (whether physician or patient) demands modes of narrating experience that diminish complexity in order

to be understood. This understanding can only stretch so far, given the limits of linear, conventional narration. As you explore the collection within this issue of *Ars Medica*, immerse yourself in the ways in which the arts—reflected here in visual form, prose, and poetry—are one way that unspeakable understanding can be conveyed across difference. As the pieces articulate the challenges, promises, limitations, and desires that arts modalities offer, we hope you will embrace the complexity of lived experience, as it unfolds within their contours, dissonances, and details.

Acknowledgements

We gratefully acknowledge the time and generosity of all of the participants who took part in the narrative study of first episode psychosis. We also thank Ms. Jasmine Sikand and the *Ars Medica* editorial team for their kind assistance in digitizing the special feature images.

References

- Hodgman, John. (2001, September 25). Welcoming remarks made at a literary reading. *McSweeneys*. URL: <https://www.mcsweeneys.net/articles/welcoming-remarks-made-at-a-literary-reading-9-25-01> [Accessed September 24, 2019].
- Rose, Nikolas. (2001). *The politics of life itself: Biomedicine, power, and subjectivity in the twenty-first century*. Princeton, NJ: Princeton University Press.
- Squier, Susan. (2007). Beyond nescience: The intersectional insights of health humanities. *Perspectives in Biology and Medicine*, 50(3), 334–347.
- St. Pierre, Joshua. (2015). Crippling communication: Speech, disability, and exclusion in liberal humanist and posthumanist discourse. *Communication Theory*, 25(3), 330–348.

Suze G. Berkhout & Eva-Marie Stern, Guest Editors

Suze G. Berkhout, PhD, MD, is a clinician-investigator and psychiatrist with the University Health Network's Centre for Mental Health. She is an Assistant Professor in the Department of Psychiatry at the University of Toronto. Her research engages questions of method and ontology within the health humanities, with a focus on using arts-based, ethnographic, and narrative methods to explore issues in philosophy of medicine and philosophy of psychiatry. Email: suze.berkhout@uhn.ca

Eva-Marie Stern, RP, MA, and Adjunct Professor, is an art psychotherapist, supervisor, and medical educator. She led the art therapy program at the Trauma Therapy Program at Women's College Hospital for over 20 years. She is a co-author of "The Visible Curriculum" in *The Health Humanities in Postgraduate Medical Education* (2018), and currently leads seminars looking at art to explore the ways we engage with one another. Email: eemstern@gmail.com