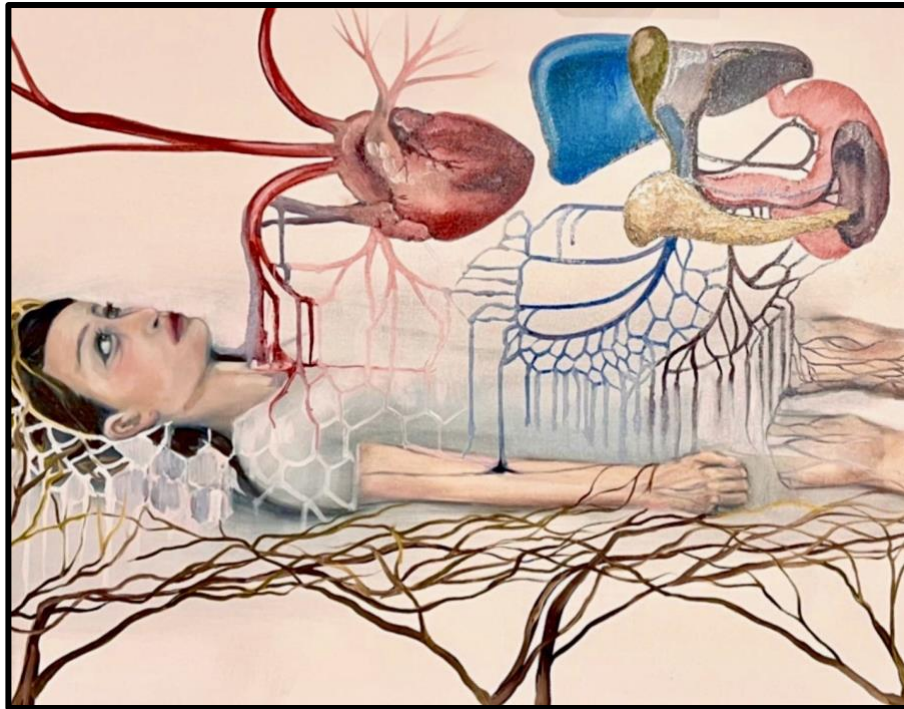


The International Journal of

WHOLE PERSON CARE

Vol. 13 No. 2 (2026): Embodiment in Medicine



Original cover art image created by Dr. Rana Awdish

Editor-in-Chief: Timothy H. Wideman

Guest Editor for the Special Issue on Embodiment in Medicine: Dr. Rana Awdish

Managing Editor: Emily Mannard

Editorial Assistant: Fatima Amari

Contributing Editors: Dr. Mark Smilovitch, Dr. Sandra Derghazarian, Dr. Krista Lawlor, Dr. Allen Steverman, Dr. Colleen Farrell, Dr. Jacqueline Pflaum, Dr. Lakshman Swamy, Dr. Leonard Berry, Dr. Susan Hata

The International Journal of Whole Person Care

Programs in Whole Person Care

Department of Medicine, Faculty of Medicine and Health Sciences

McGill University

3640 University Street, Montreal, Quebec, Canada

Table of Contents

Embodiment in Medicine Contributions

Editorial

Embodiment in Medicine Rana Awdish	1-3
--	-----

Narrative Perspectives

What Measurement Cannot Hold: Reflections of a Research Nurse in Lupus Care Monica Gamez-Perez	4-10
Kintsugi: The Body That Keeps Returning Kalli Stilos	11-14
Art as a Way Through Suffering: Embodiment in Medicine Medha Cherabuddi	15-17
Eclipsed Kara Zivin	18-22
Losing a Leg—and Myself Avra Wing	23-25
Presence is the Practice: A Reflection on Embodiment, Illness, and the Clinical Encounter Jess Bunin	26-31
On Becoming the “Good Doctor” Brooke M. Buckley	32-36
The Ways Her Body Speaks Megan H. Pesch	37-39
The Cellar Held: Knill’s Magic Underworld and the Practice of Whole Person Care Richard Wainright	40-48
Embodiment <i>IS</i> Medicine: Reclaiming the Non-Verbal Intelligence of the Body in Modern Medicine Marina ‘Heron’ Tsaplina	49-56

The International Journal of Whole Person Care

Programs in Whole Person Care
Department of Medicine, Faculty of Medicine and Health Sciences
McGill University
3640 University Street, Montreal, Quebec, Canada

WHOLE PERSON CARE

Recipients of the McGill Whole Person Care Trainee Writing Award

- | | |
|---|-------|
| The Breath Before the Cut: A Resident's Perspective on Surgery, Music, and the Body
Sarah Klapman | 57-60 |
| Between Recognition and Neglect
Mohamed Farris Masthan M. | 61-64 |

Additional Contributions

Storylines

- | | |
|---|-------|
| From Hollowness to Hope
Sandra Derghazarian | 65-66 |
|---|-------|

Commentary

- | | |
|---|-------|
| Countering Social Death: A Conceptual Framework for Radical, Community-Supported Palliative Care in Whole Person Medicine
Oyeleke Stevens Olaide, Adekunle A. Adebayo, David O. Oladokun [Seun Oladokun], Olufunmilayo Ikotun | 67-76 |
|---|-------|

EDITORIAL BY SPECIAL ISSUE GUEST EDITOR

EMBODIMENT IN MEDICINE

Rana L. A. Awdish, MD, MACP, FCCP

Henry Ford Hospital, Detroit, Michigan, United States

rawdish1@hfhs.org

KEYWORDS: Embodiment; Trauma; Healing; Medicine; Community

Like so many of us whose lives are upended by illness, grief or trauma, I needed to believe in an after. I'd subscribed to medicine's most idealized version of itself, that vectored trajectory away from illness and towards full restoration, even if it was mostly fantasy. As an intensivist, the construct allowed me to believe that if I was focused, skilled and knowledgeable, the patients would get better. When I went into hemorrhagic shock from a ruptured hepatic adenoma during pregnancy, and became a critically ill patient myself, I trusted medicine to get me out (Awdish, 2017). I knew it wouldn't be easy, and I could accept some dips and plateaus, but the overall trajectory had to be insistently and undeniably forward. Had someone drawn the actual recursive, tangled, and decades-long course my ongoing healing has followed, I would have banished them from my ICU room, if not my life. Permanent exile.

Ironically, this longing for a linear path resulted in estrangement from my own body. When my healing didn't resemble a perfect narrative arc of redemption, I began to view my body as a source of betrayal. It became something to be managed and contained, a site of ongoing failure. My training had so predisposed me to pity sick bodies that I could only see my own as a broken object to be corrected. To regard it differently, as an instrument of knowing worthy of reverence, meant unlearning nearly everything. This is something I explore in my more recent book, *After Shock: Learning to Reinhabit My Body After Illness* (Awdish, 2026).

This is the territory this issue asks us to enter, and it has been humbling to spend the last several months living inside these essays as guest editor. Each of these writers, physicians, nurses, researchers, and a few who arrived at this subject through the body of someone they love, has offered a unique perspective. Read together, they do not agree on what embodiment means. They circle it from different distances, using different instruments: a notebook left on a windowsill, a broken bowl gilded back together, a childhood at

the piano, a cellar during war, a leg that is no longer there, a puppet used to invite physicians back into their own bodies.

The threads that run through these pieces reveal something about our medical culture, and the environment in which we are attempting to heal. We see the cost of medicine's insistence that our bodies' needs are inconvenient; hunger, thirst and sleep framed as obstacles to override in service of the work. We revisit the acculturation process that trained us to equate numbness for competence, and the pain of self-erasure. In contrast, these pieces assert that full attention to a patient's body requires first knowing and accepting our own very human frailty and clear-eyed acknowledgment of the structures we work within.

These are the structures that decide which bodies receive care, and which do not. We read the experience of a trainee in community medicine who recounts times when genuine suffering couldn't be translated into the paperwork required to mitigate it. We see a person become illegible in the eyes of a system that requires rigid case documentation. A clinician learns a dialect that she was never taught through her own child's autism. And a nurse working with lupus patients writes about the violence of a system built purely on measurement, where a patient rates her pain a six because that's the only vocabulary the chart accepts. We are reminded that so much of what matters resists measurement.

Some essays sit inside a body already permanently changed by illness or injury and ask what it means to go on living there. One writer describes losing her leg in an instant on a Brooklyn street, and the years since, in which she has come to understand herself as three different women. Another addresses a cavernoma she carried unknowingly for over forty-five years, tracing its unfolding from incidental finding to totality and finally to an uneasy, watchful quiet. A palliative care nurse writes about mending a broken bowl with gold, discovering piece by piece that the break itself could become visible, load-bearing, even luminous. I appreciate these testimonies of what it means to live visibly altered and undeniably whole.

I do not think it is an accident that so many of these essays arrive, by such different routes, at the same insistence: that the body is not simply where illness happens, but where meaning is made. This is not a new idea, though it is one we have organized our institutions to forget. Whole person care asks us to remember that this is still, underneath everything we have since built on top of it, what medicine is.

It felt important to me that the cover art for an Embodiment-themed issue be something I made with my own hands. The painting I've offered is an oil on canvas that represents the estrangement and dissociation I've often felt from within the storm of illness. My conceptualization of embodiment holds space for both the rupture and the return and is far less of an individual pursuit than an ongoing communal effort. The essays here bring that vision to life.

I thank the contributors to this issue, for their candor, and for the particular kind of courage it takes to hand your own undoing to strangers and trust that they will read it with care. I thank the editorial team at the International Journal of Whole Person Care for the invitation to guest edit this issue. My hope for the reader is that you will let these essays meet your own body as you make your way through them. Whether through a held breath, a softened jaw, an emotional memory you had not expected to meet on this page. That physical response is not incidental to the reading. It is, I think, the point. ■

References

1. Awdish R. L. *In Shock: My Journey from Death to Recovery and the Redemptive Power of Hope*. New York: St. Martin's Press; 2017.
2. Awdish R. L. *After Shock: Learning to Inhabit My Body After Illness*. New York: St. John's Press, Macmillan; 2026.

Biographical Note

Dr. Rana Awdish is the bestselling author of the landmark medical memoir, *In Shock*, and her much anticipated follow-up book *After Shock*. She is the Medical Director of Care Experience at Henry Ford Health, and a pulmonary critical care physician. Recognized as a leading voice on healing, Dr. Awdish's work has been recognized through accolades such as the Schwartz Center's National Compassionate Caregiver of the Year, and Press Ganey's Physician of the Year. She has shared her expertise through diverse dissemination channels, including *The New England Journal of Medicine*, *The Washington Post*, NPR, and CNN.

WHAT MEASUREMENT CANNOT HOLD: REFLECTIONS OF A RESEARCH NURSE IN LUPUS CARE

Monica Gamez-Perez, BSN, RN

NYU Langone Health, New York, United States

Monica.Gamez-Perez@nyulangone.org

KEYWORDS: Embodiment; Systemic Lupus Erythematosus; Clinical research nursing; Whole person care; Reiki

She tells me her pain is a six.

Not only because it is a six, but because she knows how to answer that question all too well.

There is a rhythm to clinical care that patients learn quickly: translate the body into numbers, compress unique experiences into language that fits inside of a chart. Pain becomes a number on a scale. Fatigue becomes a checkbox. The body becomes something to report on rather than something to inhabit.

When I ask instead, “What does your body feel like right now?” she pauses.

In that pause, something shifts.

As a research nurse working with patients with Systemic Lupus Erythematosus (SLE), I have been trained to observe, document, and quantify. I ensure protocol adherence, collect patient-reported outcomes, and translate lived experiences into structured data. This work is essential. It is how we build evidence, ensure safety, and advance treatment for our patients.

But over time, I began to realize that scientific rigor alone could not capture the full experience of being in a body.

The more precisely we measured the body, the further patients sometimes seemed from it.

Lupus, in particular, complicates the relationship between person and body. It is unpredictable, often invisible, and deeply felt. Patients move through cycles of flare and remission, learning to anticipate disruption but not necessarily when it will strike. Many describe feeling betrayed by their bodies, uncertain of when symptoms will return or whether others will understand the severity of what they are experiencing.

Their symptoms are real, but not always visible. Their experiences are profound, but not always easily captured.

In clinical settings, these experiences are filtered into what can be measured.

What cannot be measured often fades into the background.

Clinicians are shaped by this environment, too. Under the pressure of time and institutional expectations, we are trained to prioritize efficiency, objectivity, and control. We move quickly through patient visits, distill complexity, and focus on what can be documented.

In doing so, we often become less aware of our own bodies: our breath, our tension, our emotional responses, and how they shape our patient interactions.

Without realizing it, we begin to disconnect from our own bodies too.

Nursing, however, exists in the space between.

As a research nurse, I do not only collect data. I build relationships. I follow patients over time. I witness the subtle ways illness reshapes identity and self-perception. I sit at the intersection of system and story, protocol and presence.

It is from that space between measurement and relationship that I began to think differently about embodiment in research.

Through the HEAL-SLE study, a nurse-led pilot evaluating virtual Reiki as a complementary intervention for adults with lupus, I found myself moving between two approaches: one grounded in measurement, the other in awareness and presence.

They are not opposites. They are incomplete without each other.

Reiki, as offered in this study, is quiet. There is no physical contact, no complex instruction, no expectation of performance. Conducted virtually, it asks very little of the patient, only that they allow themselves to pause and notice.

For many patients, this is unfamiliar. Chronic illness often teaches vigilance: scanning for pain, bracing for fatigue, and pushing through discomfort. The body becomes something to manage or endure.

Over time, I began to notice how often patients arrived at their research visits already apologizing for their bodies.

Apologizing for running late because mornings were difficult.

For needing to sit down.

For brain fog.

For exhaustion.

For forgetting things during appointments.

Some rushed to visits straight from work or long commutes across the city on the subway, trying to make research visits fit into lives already shaped around symptoms, medications, and unpredictability. Many had spent years moving through the healthcare system feeling rushed, minimized, or unheard.

By the time they reached our research team, what many seemed to want most was not only symptom relief, but space.

Space to speak without interruption or judgment.

Space to be listened to without needing to prove the reality of what they were carrying.

During these virtual Reiki sessions, something different is invited.

Instead of asking the body to perform, we ask it to be.

I began to think of the body not as a problem to solve, but as a place that had, for many patients, become difficult to live in. A place where things feel unpredictable. Where certain sensations are avoided. Where trust has been slowly eroded.

In clinical care, we often focus on repairing the body, stabilizing systems, managing symptoms, and preventing damage.

But in these Reiki sessions, the work was different.

We were not repairing the house.

We were helping patients sit inside it again, sometimes without bracing.

The changes were often subtle, but unmistakable.

Patients described feeling lighter, calmer, or more at ease. One patient entered a session with shoulder pain and, by the end, reported that it had resolved. Another said, "I didn't realize how tense my headache was until it was gone." One patient shared that she normally relied on medication to help her sleep, but after sessions she found herself falling asleep easily on her own. What stayed with me was not only the change in sleep itself, but the relief in her voice when she described finally feeling at ease enough to rest.

Several patients came to look forward to these sessions because they offered something increasingly rare: a dedicated space to pause, notice, and simply be.

These moments are easy to categorize clinically, to attribute to the relaxation response, expectation, or placebo effect.

Those explanations may be valid.

But they do not fully capture what is happening.

What I witnessed was not only a change in symptoms, but a shift in patients' relationship with their bodies. For brief periods, patients were no longer bracing against their bodies. They were living within them.

Working within a research framework, I remain attentive to the importance of scientific rigor. Questions about methods, reproducibility, and bias are necessary and appropriate. Integrative therapies must be studied with the same care and scrutiny as any intervention.

And yet, some aspects of healing do not fit easily into standard instruments of measurement.

Embodiment is one of them.

It shows up in pauses, in breath, in the softening of shoulders, in the exhale that comes without instruction. It is relational, dynamic, and deeply personal. It does not always translate cleanly into data points.

The HEAL-SLE study attempts to hold both measurable outcomes and patients' lived experiences. But even within this design, it becomes clear that what is most meaningful may not always be what is most measurable.

This is not a failure of research, but a reminder of its limits.

Embodiment, in this context, becomes both a clinical and ethical consideration.

For patients with lupus whose symptoms are often minimized, misunderstood, or rendered invisible, reconnecting with their bodies can be deeply validating. It offers an alternative to the dominant narrative of dysfunction, allowing awareness without judgment.

It does not replace medical treatment.

It does not eliminate disease.

But it changes the landscape on which illness is experienced.

This work has also changed me.

Before this study, I often moved from task to task without noticing my own body. Like many clinicians, I measured my effectiveness by efficiency and productivity. Through this work, I became more aware of how often I moved through my days holding tension, pushing past fatigue, and treating my own body as secondary to my work.

The more I invited patients to pay attention to their bodies, the more I realized I needed to do the same.

I still document pain scores.

I still follow protocols.

I still contribute to systems built on measurement.

But I am practicing differently now.

I notice when a patient hesitates.

I listen for what is not said.

I pay attention to my own breath in the room or on the screen.

I have come to understand that care is not only what we do to the body, but how we are with it.

In a system built on metrics, embodiment can feel secondary to what can be seen and recorded. Yet again and again, I return to that pause.

In these pauses, I am reminded that there is a person living around every number we collect.

At the end of a Reiki session, I ask the patient how she feels. She does not answer right away. She lowers her gaze, and for a moment, she simply notices.

She is not translating what she feels into a number or searching for the “right” answer. She is simply noticing her body and experiencing what is there without judgment: the steady movement of her breath, the easing of her tension, the unfamiliar comfort of being still.

In the silence, I allow myself to be present with her. I become aware of my own breathing. I notice the subtle rise and fall of my chest. The gentle exhale that follows.

I notice the impulse to move forward, ask the next question, or record what she has said. Instead, I remain quiet.

These are the moments that surround the data but may never become data points.

In this moment, I have the privilege of witnessing a person fully present within her body.

For once, her body is not being asked to prove its pain or account for its limitations.

Her body is not a problem to solve or something to be changed, quantified or explained.

For these few quiet moments, her body is simply where she is, and I am there with her.

In that shared pause, she returns to her body. And I return to mine. ■

Biographical Note

Monica Gamez-Perez, BSN, RN, is a clinical research nurse in the Division of Rheumatology at NYU Langone Health Orthopedic Center, where she has more than eight years of experience in lupus and autoimmune disease research. Her work focuses on improving patient experiences in clinical research and advancing compassionate, holistic approaches to whole-person care. She served as principal investigator of HEAL-SLE, a nurse-led pilot study evaluating virtual Reiki for adults living with lupus. Ms. Gamez-Perez is a graduate of the Lerner Holistic Integrative Health Nursing Fellowship and a current Nursing Science Fellow. She is pursuing graduate study in the Adult-Gerontology Primary Care Nurse Practitioner program at NYU Rory Meyers College of Nursing, facilitates a lupus patient support group focused on education, community, and empowerment, and is pursuing Reiki Master certification.

KINTSUGI: THE BODY THAT KEEPS RETURNING

Kalli Stilos, RN, BScN, MScN, CHPCN(C)

Advanced Practice Nurse, Palliative Care Consult Team, Sunnybrook Health Sciences Centre, Toronto, Ontario, Canada

Adjunct Lecturer, University of Toronto, Toronto, Ontario, Canada

kalli.stilos@sunnybrook.ca

KEYWORDS: Palliative care; Whole person care; Resilience; Reflective practice; Kintsugi

It fractured in a moment, yes, but the breaking bowl echoed long after the sound faded. Pieces scattered, some sharp, some softened at the edges, some so small they seemed impossible to recover. When I first sat with the fragments, I was thinking about loss.

This is where the work begins.

I sit with the fragments, shoulders rounded over the table, fingers tracing uneven edges, much like I sit with my patients and their families at the bedside, leaning forward, attentive, aware that every piece matters, even the ones that seem too damaged to hold. There is a quiet kind of assessment that happens. Not clinical, not detached, but deeply human. What fits? What is missing? What will never return?

Then comes the reset. I breathe. I clear space. I loosen my shoulders and accept that the bowl will not return to what it once was. This is the same acceptance I must find at the bedside, when cure is no longer the goal, when time shifts from something we measure to something we hold.

The first piece is always the hardest to place.

My hands hesitate. The glue is unforgiving. Too much, and it spills over. Too little, and nothing holds. It sticks to my fingers. My shoulders are tense. It is messy and uncertain. I press the fragments together anyway.

Relief comes in small, almost surprising waves. A piece holds. Just one, but it holds.

This is the moment I recognize from my work: when pain is eased, when a patient finally exhales without tension, when I sit close enough to hear breathing soften or feel a hand unclench inside mine, when a family member's shoulders lower because someone has told them the truth with kindness. These are not grand resolutions. They are small alignments. But they matter.

Piece by piece, the process continues.

There is a release in repetition. Apply, hold, wait. Apply, hold, wait. I begin to trust the rhythm, even as my hands grow tired. There is something therapeutic in allowing the work to unfold without forcing it to become whole too quickly.

Frustration creeps in.

The bowl resists me. Edges do not align. Gaps remain. The shape feels unfamiliar. I feel the pull to discard it, to throw it away because it no longer resembles what it was supposed to be.

I know this feeling too well.

It lives in the moments when families ask, "Why is this happening?" and there is no answer that satisfies them or me. It lives in anger, impatience, and grief that has nowhere to land. It lives in a quiet resistance to endings and to the reality that some things cannot be fixed.

There are times I want to walk away, from the bowl, from the bedside, from the physical weight of witnessing lives unravelling. The heaviness settles into shoulders after long shifts, into tired feet, into the body that keeps returning despite itself.

I choose to keep going.

Because something shifts when I allow imperfections to exist without trying to erase them. The bowl begins to take form again, not its original form, but a new one. Uneven, marked, undeniably altered.

Unexpectedly, there is awe.

The lines where it broke remain visible, traced in gold. The gold catches light in ways the unbroken bowl never could.

What once felt like damage begins to feel like evidence, survival, effort, of care.

I feel a quiet excitement return. Not the excitement of restoration, but recognition. The bowl is not less because it is imperfect. It is more because it carries its history openly.

This is what I learn repeatedly in palliative care.

We are not here to restore life to what it once was. We are here to hold what remains with honesty and compassion. We sit in the mess, the grief, the anger, the unfinished conversations, the fragile moments of connection. We witness the breaking and the reforming, knowing that wholeness does not require perfection.

The process is not clean.

It is sticky with emotion, uneven pace, and often deeply uncomfortable. There are days when nothing seems to fit, when gaps feel too large, when outcomes feel unsatisfying.

Still there is meaning.

Because in staying, in tending, in gently pressing pieces together even when they resist, something profound happens. Not healing in the way we often define it, but another kind of healing, one that allows loss and love to exist side by side.

Anger rises in me as I look at what this piece has become. What was once smooth and rounded now feels altered. One side remains raw. Its seams show. I find myself trying to match each piece back exactly as it was, but it becomes clear this is impossible.

And yet, the gold moves through it, threading broken lines, softening what feels harsh, illuminating what I once saw only as flaw. I have reinforced it with as much glue and care as I can offer. It stands now, finished, though not complete in the way I once imagined.

There remains a piece too small to place.

Its absence leaves a visible opening, a space that holds sadness and happiness, courage and trepidation, uncertainty and endurance.

And still, it remains.

It shows up, just as I have, day after day, for twenty-five years.

What mending this bowl ultimately teaches me is that whole person care is never only cognitive or emotional, it is embodied. It lives in how we sit beside suffering, how we tolerate silence, how we notice breath, posture, touch, fatigue, and absence. My patients experience illness through their bodies, and I experience caregiving through mine. Neither can be separated from the care itself.

This bowl has become something more than it was.

It is a quiet badge of honor, one that holds a story only I fully understand. A story of who I was before oncology and palliative care, and of how, through every fracture and repair, I have been shaped into the nurse I am today.

This process reflects my tenacity that this quiet persistence, this refusal to abandon broken pieces, is who I am.

It is exactly who I am at the bedside.

The bowl is never the same. ■

Biographical Note

Kalli Stilos, RN, BScN, MScN, CHPCN(C) is an Advanced Practice Nurse with the Palliative Care Consult Team at Sunnybrook Health Sciences Centre and an Adjunct Lecturer at the University of Toronto. Her clinical, educational, and research work focuses on improving palliative and end-of-life care, communication, and healthcare provider well-being. Recent scholarship includes studies on advances in end-of-life care in Canada, timely access to palliative care, and the unique needs of adolescents and young adults with cancer. She has co-led quality improvement initiatives recognized by the University of Toronto's Department of Family and Community Medicine, including the award-winning Goals of Care Simulation program.

ART AS A WAY THROUGH SUFFERING: EMBODIMENT IN MEDICINE

Medha Cherabuddi MD

PGY-6 Senior Chief Fellow
Pulmonary and Critical Care Medicine
Henry Ford Hospital, Detroit MI
mcherabuddi@gmail.com

KEYWORDS: Art in Medicine; Narrative Medicine; Embodiment in Medicine; Patient-Centered Care

It was just another Wednesday morning in one of the largest intensive care units in the country. I held my still-warm chai in my hands, hoping it would carry me through the call shift. As I pushed open the heavy ICU door to my sickest patient's room, there was a middle-aged mother suffering from progressive respiratory failure from years of lung and heart disease receiving invasive mechanical ventilatory support. Although she was surrounded by lines, tubes, drips and machines, she seemed so alone and sad, and my eyes settled on a notepad resting on the windowsill. The blinds cast shadows across the floor, interlaced with the thin rays of sunlight that sneaked between them. The room was filled with monotonous shades of cream, grey, and blue, with hints of sage green, colors intended to soothe yet somehow served as quiet reminders of illness and vulnerability.

Her handwriting evolved over the creased pages, there were entries in steady script while others seemed abrupt and trailed off mid-sentence. One note described her fear of leaving her son behind. Another reflected frustration at being unable to communicate. As I stood there reading, I became aware of my own body, the tension in my neck, the firmness of my grip on the paper, the heaviness settling in my chest. These pages allowed me to glimpse the uncertainty that accompanied her illness, as well as the hope that gave those experiences meaning. She was no longer simply the patient with severe respiratory failure. She was a person trying to make sense of what was happening to her.

Throughout my training, I learned to notice subtle trends such as the few millimeter lung nodule and fine breath sounds. In sharpening this attention, I was afraid I had begun to lose another: attention to what could not be measured such as the way illness reshaped the life beyond the hospital room. My jaw unclenched, my fingers relaxed, my breathing slowed. I stayed with the page a little longer than I normally would have. The silence no longer felt like time I was wasting. It felt necessary. Looking at a canvas taught me to stay with uncertainty, and standing beside her journal, I realized I was doing the same thing. Instead of asking what diagnosis or intervention came next, I ran my fingers over the indentation her pen had left in the paper and imagined the effort it must have taken to press those words onto the page while struggling for breath. The monitors and ventilator screens were cold, smooth, and unyielding. The paper beneath my fingertips was creased and soft from repeated use, her handwriting uneven where exhaustion had interrupted her thoughts. In a room crowded with machines, it was those human textures that caught my attention.

Our medical training has always taught us that efficiency is paramount. Art has taught me another way of looking. It encouraged me to pause long enough for details to emerge such as the words she crossed out before trying again, the way fear appeared over and over while anger never did. None of these observations changed the ventilator settings, but they changed the person I believed I was caring for.

I carried the notebook into rounds and handed it to my residents. The room grew quieter as each person read a few lines. Conversation drifted away from reports of ventilator settings and laboratory values toward the young son waiting in the hall, and the woman in the room enduring the silent turmoil. Her journal gave us a language for empathy. It reminded us that even when a patient cannot speak, they continue to communicate. I wondered then about the patients who have no journal to offer us. Art had taught me to slow down and look more closely, and perhaps the same attention could help me recognize what patients communicate without words, through gesture, silence, and the traces of a life surrounding the hospital bed. As I read her words aloud, my chest tightened and I slowed without meaning to. On the drive home, that heaviness had softened, replaced by the quiet reassurance that we had tried to find a connection.

That evening, with a pencil and paper, there was space to exhale and feel lighter. I was not trying to reproduce her face or tell her story exactly. Instead, I found myself tracing the feeling of holding those pages, the weight in my hands, the pauses between her words, the quiet loneliness of a room filled with machines. I began sketching the room, the looping ventilator tubing, the intravenous lines crossing one another, the careful order hidden inside what first looked like chaos. As the pencil moved across the page, I realized the nurses had created that quiet order every day, making space for care amid uncertainty. The act of drawing did not erase sadness. It allowed me to move through it.

Art has taught me to listen not just with my mind, but with my body, to notice tension, stillness, and hesitation, and to recognize that these too are forms of knowing. In medicine, I often carry patients in my

mind, leading to containment and unease. This patient taught me that stories can also be carried in the body. Art gave me a way to notice that burden, make space for it, and ultimately transform it into connection. When I draw or paint after a difficult day, the weight I carry gradually eases. The stories I could not leave behind begin to move instead of remaining trapped inside me. I began to see this as a newfound form of efficiency, not one that required more time, but one that changed how I moved through the work already before me. Art has become the place where I can carry my patients with emotion and, eventually, carry their stories more gently.

Confidentiality Statement

The patient provided consent for me to view the notebook and to share its contents in a reflective piece, although the eventual scope and form of the piece had not yet been determined at the time. Through this work, I have sought to honor the significance of the patient's journey while safeguarding their privacy through the removal or modification of potentially identifying details.

Biographical Note

Medha Cherabuddi is a third-year Pulmonary and Critical Care Medicine fellow with an interest in pursuing a career in academic medicine. A lifelong artist, she has been painting since elementary school and particularly enjoys travel sketching. Her artwork has been exhibited in Hyderabad, India, and her visual and reflective works have appeared in various journals featuring narrative medicine. Outside of medicine, she finds joy in documenting everyday moments through photography and gratitude journaling, recreating South Indian family recipes, and planning meals for busy weeks in the ICU. Her creative practice continues to shape how she approaches observation, reflection, and connection in medicine.

ECLIPSED

Kara Zivin, PhD, MS, MA, MFA

Marcia A. Valenstein, MD, Collegiate Professor of Psychiatry, Professor of Obstetrics and Gynecology, and Professor of Health Management and Policy
University of Michigan, Ann Arbor, Michigan, United States
kzivin@umich.edu

KEYWORDS: Seizure; Cerebral cavernoma; Neurology; Unexplained symptoms

Contact (2022)

At first, they called you *incidental*. As if to say, *nothing to see here*. They left unspoken, *we still don't have answers about the lightheadedness when you stand or the imbalance between your ears*.

They mentioned you because they'd found something observable, just not what they sought when they placed me in that tube. No one had previously searched inside my skull, so before this scan, we had no way of knowing how long you'd resided there. A bright core surrounded by a dark ring. An inverse of the moon blocking the sun.

Perhaps you'd arrived at my birth, yet for over 45 years, you'd stayed dormant. They reassured me that despite your appearance as a cluster of cells, enlarged and thin-walled vessels in the shape of a berry, you were not malignant. As far as we knew then, you would remain unremarkable.

Partiality (2023-March 2024)

You stayed stealthy, even as your surrounding atmosphere began to shift. Subtle enough that at first, no one held you responsible. A few weeks after the first detection, as I sat typing on my laptop, I began to lose my words, my language, if only for a few seconds. I might not have even noticed, had the searing chest pain not immediately followed, then disappeared without a trace. A storm that blew in and out in less than a minute. My ability to speak, my voice returned, and I continued the task I'd paused a moment earlier.

Shake it off. I tried willing myself into ignoring you. Yet thoughts about the risk of cardiac illness and death in women, and in my family, also lodged themselves in my head. Then the mantra, *we should have known*, when my father's keen scientist's mind began to falter. Only too late did we realize that what appeared as cerebral deterioration likely represented a lack of oxygen to his brain as his arteries clogged to occlusion.

Those losses and missteps haunted me, making me unwilling to leave my fate to chance. After all, I still did not know what caused the lightheadedness that led me to you. When I called my doctor's office to report the scramble in my mind and the pain in my chest, they said, *if it happens again, go to the emergency room*. Mere hours later, I did not make it to the end of the road while walking my dog when the same sequence emerged. I came home and got into the car.

It did not cross anyone's mind to look for you then. They hooked monitors to my chest, not my head. While waiting for the attending physician to arrive, I sat down and stood up and watched my heart rate spike, then drop. Months later, after a tilt table test, we would figure out the source of my dizziness. But that still did not explain the flares you caused.

Losing words became more frequent and disruptive. I tried to convince myself that if I could just avoid the triggering one, I could prevent the ache altogether. Those moments caused me to become mute, or garbled noises spewed from my lips. Yet as soon as the sensation receded, the memory of the offending word disappeared, so I could never be sure which one made my heart race.

You made me afraid to speak.

Less than six months after they first found you, they searched again. They called you *stable*, though the ground underneath my feet felt anything but. A lengthy neuropsychology evaluation attributed my "cognitive difficulty" to stress and poor sleep. Even when signs became glaringly obvious, it's as if you still had me under your spell, hiding, waiting.

A few weeks after that second sighting, I found myself on the floor in my bedroom. I woke up not knowing how I got there. I did not know then that I had lost consciousness. The next morning, I stepped into the bathroom and stared in the mirror at what looked like a purple ring around my right eye. An unfortunate collision with a stealth laundry basket in my path.

My father too had landed for good just outside his bathroom.

Why could no one see for nearly a year that even though your appearance had not yet changed, you played a role in my decline? Even my therapist thought what wreaked havoc on me stemmed from panic attacks.

Yet episodes arrived during mundane tasks. Why would walking, doing laundry, or typing leave me disoriented, coupled with wrenching pain?

The routine became all too familiar. As soon as my words started to falter, like a needle scratching a record, I knew what would come next. If only pressing my hand over my heart or holding my breath would prevent the burn. Only when I finally met an epileptologist did someone understand how and why you ravaged my mind and heart the way you did with increasing frequency. She told me my symptoms were seizures.

I became a storm chaser, a light seeker, an information gatherer. Tapping into my skills as a health researcher, I wanted to predict you, understand you, as if with knowledge, I could coax you into retreat. I decided to collect data about you each day. When did I exercise and for how long? What time did I go to sleep? Did I wake up in the night? Did I drink any caffeine or alcohol?

For a while, it seemed like you didn't want me to listen to books, yet you didn't seem bothered at night. Only later would I learn you stayed active all the time, even when I did not register your presence.

Totality (April-May 2024)

They began planning how to handle you. First, they tried medication. But instead of brief episodes of confusion, it felt like my brain had become mud. And you still came for me anyway. Then, they talked about removing you. A laser with a tip like a soldering iron could use heat to extinguish you. Or they could come after you with a drill, a saw, a metal plate, screws, and stitches. One approach sounded less invasive, less proven. The other, more certain, more violent. I pictured both, and my body recoiled. I could not risk losing language, memory, emotion, all possible, given your location. You became impossible to ignore, and I risked injuring myself or someone else by avoiding you. But given that I did not lose consciousness, I told myself I could still drive and did.

Back in 2017, during the solar eclipse in North America, my father and I made plans to travel to the path of totality in 2024. He would come from California to Michigan, and we would drive to Ohio to see one of nature's most awesome sights. We did not know then that he would not make another trip around the sun. I kept my promise, traveling nearly one hundred miles alone. As if the stars aligned as well as the sun and moon, for that single day, you gave me a reprieve. When looking upward, my eyes covered by protective lenses, I did not see the flares as the moon blocked the light and the outer ring burned into the sky.

Again, I found myself at a loss for words to describe totality, but this time my brain stayed clear. Instead, I joined countless souls who witnessed what the mind could not fully comprehend as the sky lost its color on that otherwise bright sunny day.

After I returned home, you came roaring back. A few weeks later, we finally saw that you had brightened. The size of a pencil eraser, inside my skull, just above my left ear. You had sprung into action, and we could finally witness evidence of your metamorphosis. Upon spying you on the screen, they wanted to measure your impact. For three days, I wore electrodes attached to my head, covered by a thin scarf, connected to a receiver in a tangle of colored wires. I looked like a cancer patient, and the tape tore the skin from my forehead. They instructed me to push a button at the onset of each jolt.

The readout confirmed that the word scrambles and the chest pain stemmed from you, not some other part of my brain. Apparently, you generated even more activity than I had recognized. I had thought my poor sleep led me to have more seizures, when instead, we found the seizures disrupted my sleep.

Over two years had passed since the lightheadedness had begun, and a year and a half since you appeared as an aside. The path forward still looked dark, with minimal light to illuminate the way forward.

Penumbra (June 2024-October 2024 and beyond)

I tried to avoid you. If I appeased you, could I avoid the tools and violence needed to remove you? I agreed to try a different medication, starting slowly. That summer, you became dormant, and my mind seemed clear. My chest didn't ache. But you had other plans.

This time, when you stole my consciousness, I was not alone. My husband witnessed you making me thrash on the bed, then run into walls. The bitten tongue, the lasting muscle aches, the morning of the black eye a year earlier finally made sense. When we reported the morning's events, the doctor asked why I had not increased my medication dose. I had thought I'd escaped the shadows. I would not make that mistake again. As I started a higher dose, the debate about excavating you continued.

I needed a fresh perspective. I sought someone who had dedicated her life to understanding how to tame or remove you. When I watched her videos and read her papers, I felt drawn to her leadership in a patient organization for those who suffered like me or much worse. I got on a small plane with scans on a USB drive and in my patient portal. If only we'd done something similar when my father still had a chance.

She sat with me for over an hour as I sank into the only couch I'd ever witnessed inside a doctor's office. She compared my scans to one another, pointing at you on her screen, and outlining how you had morphed since first contact. I wanted her to tell me why. Less than one-half of one percent of people have this extra companion. If you'd really been there since birth, what did that mean? Some questions remain unanswerable.

She agreed with my home healthcare team's assessment to watch and wait. If the medication worked, I could avoid the scalpel. Unlike a stroke requiring immediate action, which my neurologist father had spent his career treating, you would ooze slowly, giving us time to pinpoint the glow and the size of the rings.

Two months later, when I donned the electrodes for another three days, they did not find evidence of seizures. But the solar flares continued just below my ability to detect them. Becoming asymptomatic represented a crucial step in preventing further damage. It had taken a long time, riddled with many wrong guesses and uncertainties, well-meaning, yet inherently flawed.

I check for traces of you. I picture you there, waiting.

Two years on, you've stayed quiet. They said I had a 20% chance that you would bleed again within five years. ■

Biographical Note

Kara Zivin, PhD, MS, MA, MFA, is a mental health services researcher in Ann Arbor, Michigan. She is the Marcia A. Valenstein, MD Collegiate Professor of Psychiatry, Professor of Obstetrics and Gynecology, and Professor of Health Management and Policy at the University of Michigan; Research Career Scientist at the Department of Veterans Affairs; and Senior Health Researcher at Mathematica. Her debut memoir, *Persevered: A Maternal Mental Health Memoir* (Swallow Press/Ohio University Press, 2026), tells the story of her mental health crisis surrounding pregnancy, and how she transformed that experience by combining data (research expertise) and story (personal narrative) to increase public awareness about women's mental health conditions. She has a left temporal lobe cerebral cavernoma.

LOSING A LEG—AND MYSELF

Avra Wing

avragwing@gmail.com

KEYWORDS: Amputation; Self-image; Identity; Sexuality; Disability

On a March day in 1990, I was walking around the corner from my home in Brooklyn, carrying my three-year-old son, when a car jumped the curb and rammed into us. My child wasn't hurt. My right leg was destroyed from the knee down.

I was 40 years old and very active: I lived in a narrow brick house with steep stairs, and I had another son, then nine. I was taking modern dance classes in a loft in downtown Manhattan, and though I was never much of a dancer, I loved feeling strong and somewhat graceful. My first novel was about to be published, and there was already talk of a movie deal.

The EMTs who had rushed to the scene took me to Bellevue Hospital, where I was fortunate that an excellent surgeon would perform the amputation. But there was a disconnect between her ability and her empathy. I remember begging her to do whatever she could to save my leg, even as I was being wheeled into the OR. She stopped, turned, looked down at me, and said, "We know what we can do and what we can't do. Now you're being irrational."

Maybe so. Clearly, though, I understood what was happening and was coherent enough to express my distress just a few hours after being hit by a huge Olds 88. Perhaps shutting me down in this way was a means of distancing herself from me as a person so that she could cut away a leg. I imagine surgeons must learn to repress, or, at least, conceal, some basic sense of horror at the idea of "dismantling" a body.

In truth, I myself questioned if I even was a person anymore—or, if I was, if I was still a woman. After all, female legs have been considered markers of desirability for centuries. I had dreams in which the connection between my leg and my sexuality was explicit. I can't speak for other amputees, but losing a

limb undermined my entire sense of self—my feeling of bodily integrity. This was more overwhelming than the PTSD resulting from the accident. My friends and family—especially my children and husband—treated me with love, trying to assure me I was still the same to them. But to the doctors I was a case. And I wasn't sure what I was. I felt disconnected from who I had been in the past and had no reference point for who I was supposed to be going forward. I see now how, although for different reasons, that perhaps both the surgeon and I had emotionally removed ourselves from what was happening.

Denial and magical thinking were the only tools I had to withstand my situation: maybe my leg was still there; maybe my leg would be restored. My mind held to these thoughts despite the very obvious physical evidence. The experienced physiatrist overseeing my treatment couldn't understand why I refused to look at myself in the mirror, why I wasn't stopping by the prosthetics department to begin the process of getting a new leg—mere days after I was admitted. A friend remarked that it seemed I was expected to display “some kind of goofy stoicism.” My doctor had a system and timeline, and I was getting off track. She decided that in order for me to progress I should be transferred to the inpatient wing of the old Rusk Institute of Rehabilitation. Because most lower leg amputations are a result of diabetes in older people, she noted that the Rusk staff would be delighted to treat “a young amputee.” That was now my identity.

The former Rusk building was in pretty poor condition, but the care there was exceptional. The ethos was in direct contrast to the expectation that patients are passive vessels waiting to receive treatment. We were active participants in our recovery, dressed not in hospital gowns but street clothes, attending various therapy classes from 9 a.m. to 4 p.m. each weekday. But even here, the psychological aspects of my situation were not understood. Once, a physical therapist questioned why I didn't roll up my empty pants leg. It was a revelation to her when I answered, “Because that would mean I acknowledge my leg isn't there.” The PT then remarked she had never thought about her patients' lives before they came to her, only about addressing the physical problem she was trained to alleviate.

When I was ready to get a prosthesis, I found extremely talented and thoughtful prosthetists—the people essential to functional lives for those of us with limb loss or difference. The relationship with a prosthetist is ongoing, as bodies change, technology advances, and equipment wears out. It's never “one and done.”

Despite the instances when I felt empathy was lacking, my overall experience with medical professionals was positive. At every step, highly skilled people helped me heal. I'm aware, too, that there is a growing movement that recognizes doctors would benefit from having a better understanding not only of their patients but of themselves as well. Maybe in the future it will be a given that expertise is not considered diminished by a more humane approach. And there are also programs offered by several organizations that teach patients how to speak up for themselves. That's the other side of the equation—learning how to be the iron fist, attached to an IV, in a velvet glove.

After all these years, even though I've received excellent support, care, and counseling, I still have moments when I reexperience the shock that my leg is missing. But I no longer feel as though I've lost my identity as a human being and woman. I've had a good life—raising my boys, adopting a daughter, teaching, writing, travelling. Recognizing my physical limitations, I do see myself as disabled. That process of redefinition began at Rusk, where I was among so many others who were injured or ill—and who were also motivated, unself-pitying, supportive, and always ready to crack jokes. We soon began to refer to Ambulation Class as Conversation Class. Now I volunteer as an Amputee Coalition of America Peer Visitor, and for many years have led a writing workshop at the Center for Independence of the Disabled New York.

Recently, I have felt increasingly close to the disability community. A sense of kinship, even if I don't have the same experience as people who have been disabled from birth, has proved extremely salutary. For example, I am grateful for the concept of "crip time"—that health, equipment, or accessibility snafus might mean getting somewhere late, leaving early, or not getting there at all. I'm witnessing radical acceptance of each other's conditions and fierce advocacy.

It may seem like a contradiction, but seeing myself as someone with a disability is not the same as totally integrating the idea that my leg is gone. Perhaps living "able-bodied" for so many years makes it difficult for me to fully accept myself as having one leg, to conceive of my body image this way. There are still times I experience my initial sense of overwhelming loss, and I know buried somewhere in my mind there is a remnant of denial. My PTSD hasn't vanished completely. The accident's aftereffects are constant factors in my life, even though, with my prosthesis on, I'm able to do most of the things I did before. But when I take the leg off at night, or periodically feel the need to remove it when it's too uncomfortable to wear, I become someone else. I've been changed as much psychologically as physically. Right after I lost my leg, I felt as if I were no longer a person. Now each day I am three people who live in three separate realities in three different bodies: the person I was with two legs, the one I am with my prosthetic on, and the one I am with it off. ■

Biographical Note

Avra Wing is the author of two novels: *Angie, I Says*, a *New York Times* "notable book" made into the film *Angie*, and *After Isaac*, for young adults. Her memoir, *Stride: How I Walked Away from Trauma Toward Healing*, was published in September 2026, Avra's poems appeared most recently in *New Ohio Review*, *Image*, *Pirene's Fountain*, *Broad River Review*, and *Santa Fe Literary Review*, and a poetry collection, *Mammoth Life & Accident*, will be published in January 2027. She leads a writing workshop at the Center for Independence of the Disabled, New York. She lives in New York City with her husband and two cats. More information can be found at www.avrawing.com

PRESENCE IS THE PRACTICE: A REFLECTION ON EMBODIMENT, ILLNESS, AND THE CLINICAL ENCOUNTER

Jess Bunin, MD, MHPE

Chief Architect, All Levels Leadership

jessbunin@gmail.com

KEYWORDS: Empathy; Medical education; Patient care; Narrative medicine

The year following my second cancer almost broke me in a way the cancer itself never had. During treatment, I had something to fight. My body was a combat zone, but I understood the terms. The days brought nausea and abnormal labs, surgeries, chemo, and radiation. My sternum was so destabilized after surgery that I learned to sleep sitting up, because lying flat made the two halves grind together. My hair fell out. I hardly recognized myself in the mirror, but I had a battle to win, a timeline, and a reason to get up.

The year after was much quieter and far more difficult. I came back to work, discharged from treatment but far from healed, and found that the world had not waited. My peers had built skills, relationships, and clinical instincts while I was away. I watched them, trying to close the distance. Some days, I felt like I was watching my own career through glass. My body, which had been the center of everything for so long, suddenly felt irrelevant. I fell into a deep depression, and I did not see a way out.

I could not have foreseen how my path back would appear. It arrived one midnight, in a hospital room, in the form of a patient I will call Carol.

I was a psychiatry resident on home call when the ER physician reached me around eleven on a Friday night. He had a patient who was belligerent, refusing admission, critically ill, and not listening to anyone. He needed me to come in and declare her "incompetent."

I pulled her chart before I walked in. Carol was in her fifties with a history of breast cancer, far enough in the past that she had stopped bracing for it. She had come in that morning for a routine CT scan for a nagging headache. She went home. Her oncologist called and told her to come to the ER immediately, without explanation, and to ask for him when she arrived.

She arrived at seven that evening. Her oncologist had already left for the night. An ER physician she had never met told her she had "too numerous to count" tumors in her brain, that the breast cancer had spread, and that she needed to be admitted tonight for steroids and radiation. He moved through the facts the way you move through a checklist when you are trying to get something done.

She heard the word tumors, and her brain shut down.

For the next four hours, person after person came into her room trying to convince her to stay. She refused them all. By the time I arrived, she had been sitting in that room for five hours and had not processed a single thing anyone had said to her. I walked in and found her pacing.

We could not have looked more different. Carol, a tall Black woman with a full head of dark hair, moved through the small room like someone trying to outrun what she had just heard. I was a short white woman, my fine brown hair undecided after chemo, wearing scrubs thrown on at eleven. She had four inches on me. I probably looked like I had just rolled out of bed, which I had.

None of that mattered. Or rather, all of it mattered, and none of it was the point.

I pulled up a chair and asked her to sit, and she did, and for a long moment neither of us said anything. I reached out and took her hand. Everything went still. Not quiet in the way a room goes quiet when someone stops talking, but still in the way that happens when something true is finally being acknowledged. Tears filled her eyes, and mine too. I was sitting with a woman who had just had her world taken apart, and my body knew exactly what that felt like, because mine had been taken apart too. The fear in that room was something I recognized from the inside, and sitting with her in it, holding her hand in both of mine, I felt the kind of stillness that arrives when you stop trying to fix something and simply agree to be present for it.

She said, finally, "I don't know what's going on."

I asked her to tell me what she had heard.

She said, "I heard 'too numerous to count tumors,' and then my brain shut down."

We backed up. I asked her to tell me about herself, her day, and what she was feeling. She did. We talked, sat in silence, and cried, and I held her hand. By the time I left, she understood what was happening in her brain, the purpose of the steroids, what radiation would feel like, and what the coming weeks would likely bring. She understood not because I explained things better than the physician before me, but because I waited until she was ready to receive it.

Then she told me the real reason she would not stay. Her cat was at home, and she had made no arrangements for its care.

I stepped out and called her neighbors until I found one who would go in that night. When I came back and told her the cat was covered, she exhaled for the first time all evening. I reached up and placed my hand on her shoulder, and I could immediately feel that she needed more than that. I pulled her into a hug. She was a head taller than me, and I had to reach up to hold on, and I did. She leaned into it. We stayed there for a moment, two women, holding each other in a hospital room at midnight, and something passed between us that I have never found the right word for. It felt more like recognition than comfort, though there was comfort in it too. It felt like two people who had both been through something terrible and had arrived, briefly, at the same place.

She stayed. She got her treatment.

I drove home through empty streets thinking about what had happened in that room, and what had made it possible.

The ER physician had done nothing wrong by clinical standards. He delivered accurate information and initiated appropriate care. Yet something fractured when he spoke, and Carol had remained in the fracture for five hours. Everyone who came in after tried to move her forward without first understanding where she was. They operated from their training, their urgency, and their discomfort with a patient who would not comply. None paused to ask what Carol's body was actually doing in that moment, what it had absorbed, and what it could not hold.

Carol's experience could have unfolded differently. The outcome was not inevitable. It hinged on a series of small interventions that never happened. Had the ER physician paused to reflect before acting, called her oncologist and asked him to come in, or simply joined the conversation by phone, the trajectory might

have changed. Had he taken the time to sit with her, to clarify what she understood and what she feared, or simply shown her empathy, the situation might never have escalated to a competency evaluation. She might have received the care she needed far sooner, and with far less harm done along the way.

I had paused, not because I was a better clinician, but because I had been on her side of a conversation like that one. I knew what it felt like to hear a word that collapses everything else. My cancer had given me that. It had not made me softer or more sentimental. It had made me more precise, specifically about what presence requires and what its absence costs.

When Carol asked about my hair, I told her the truth. I told her I had just come through cancer too. That moment of shared humanity changed something between us. It gave her permission to be exactly where she was. The two of us, different in almost every visible way, both marked by illness, were trying to find solid ground. The asymmetry between us was real, and so was what dissolved it. She stopped being a patient who would not comply and became a woman who had not yet been heard. I stopped being the psychiatry resident sent in to declare her incompetent and became, for that hour, simply a person who understood something about what she was carrying.

If I were advising myself before my diagnosis, I would say this. Do not wait for your own crisis to teach you what a patient's crisis feels like from the inside. Build the skill at every stage of your career, not just once in medical school. Engage in education emphasizing narrative medicine and simulation training to develop more self-awareness. Find peers who have suffered critical illness and ask them about their journey. Engage in book or movie clubs to develop more empathy for the patient experience and connect more effectively with each patient you meet. This would not have replaced what I learned through my own illness, but it might have taught me to slow down, ask more questions, and listen more thoroughly.

The clinical encounter is always a meeting between two bodies. We do not often talk about it that way. We are trained to position ourselves as the ones who know, and our patients as the ones who receive. That framing flattens something important. Carol's body had been in that room for five hours, absorbing fear, refusing movement, holding on to the one thing she could still control. My body had spent a year learning, from the inside, what it means to lose that control. The encounter between us was not just physician and patient. It was two bodies that had both been broken open, meeting each other across a hospital room, and finding, in that meeting, something that made the next step possible for both of us.

When I drove home that night, something had shifted in me that therapy alone had not been able to touch. I had spent a year feeling like I was disappearing. My peers had moved past me while I was busy surviving, and I feared I would never fully close the gap. The depression I carried was not only about the illness itself.

It was about the fear that I had lost my place, that I would never again feel like a doctor who had something real to offer.

Carol gave me something back that night. The grief lingered as I drove home, and the gap between my peers and me remained. But for the first time in a year, I understood what my illness had actually given me, and that it mattered. I had been on the receiving end of the worst conversation a patient can have. I knew what it felt like to be the body in the bed, to have information land before you are ready, to need someone to slow down and stay. That knowledge was not incidental to my clinical work. It was at its center.

I left that hospital with something that, cautiously, felt like hope. Driving home, I came to believe that my experience was not a year of random, meaningless suffering. Instead it made me capable of something I could not have offered before: the ability to sit with another in their suffering and bring comfort. It also made me realize that I wanted to keep practicing medicine, and that wanting was something I had not felt in over a year. I was not behind my peers in any meaningful way. I could still learn the physiology of medicine that I had missed, but I had learned what it costs a patient when a physician cannot be present with them, because I had paid that cost myself. This was a lesson that I could not have learned from textbooks, and that I would use for the remainder of my career.

That recognition was the first real step out of the depression that had been swallowing me. Medication and therapy had both played their roles, but this was the moment I understood that my body's history, everything it had absorbed and survived and learned, was not a liability I was carrying into the clinical encounter. It was what made the clinical encounter possible. The illness had not derailed my career. It had deepened it in ways I was only beginning to understand.

Medical training teaches us to manage the body in front of us, but rarely to inhabit our own. We learn to override fatigue, suppress uncertainty, and distance ourselves from what we feel so that we can function in environments structured by hierarchy, time pressure, and loss. That distancing has a cost. It costs us the knowledge that arrives not as thought but as felt recognition, the kind that lets you walk into a room full of fear and know, without a checklist, exactly what to do. When we train clinicians to leave their bodies at the door, we are not making them more objective. We are making them less complete.

Carol is the reason I stopped asking, "Why me?" She is also the reason I believe that the most precise clinical instrument any of us carries is not what we learned in training. It is what we have lived. ■

Biographical Note

COL(ret) Jess Bunin, MD, MHPE is Co-Founder and Chief Architect of All Levels Leadership, Certified Executive Coach, and author of *Self-Awareness and Trust: Leading Healthcare Teams from the Inside Out*. A graduate of West Point and Tulane University School of Medicine, she completed her Internal Medicine and Psychiatry residency at Walter Reed Army Medical Center, served as a Psychiatrist at West Point and completed a Critical Care Medicine fellowship. She has since held leadership roles throughout the physician lifecycle to include Program Director and Associate Dean. She retired in 2023 after 23 years in the Military, deploying to Iraq as a Psychiatrist and Afghanistan as an Intensivist. She is passionate about developing future leaders through faculty development, coaching, and mentorship.

ON BECOMING THE “GOOD DOCTOR”

Brooke M. Buckley, MD, MBA, FACS, DipABLM

Henry Ford Health, Detroit, Michigan, United States

BBUCKLE3@hfhs.org

KEYWORDS: Physicians; Professional identity; Burnout, Professional; Well-being; Medical education; Internship and residency; Humanism

It was my final year of surgical residency. A 17-year-old boy wrapped his parents’ SUV around a tree. In the trauma bay, we thought he was stable. But while in the CT scanner – where we had been trained that a patient should never crash – it became obvious he wasn’t. The room erupted into motion. I opened his chest. A shocked housekeeper covered my shoes so they would not be soaked in blood. My intern tucked in beside me, sharing the motions of trying to save a life.

I held the boy’s heart in my hand with gentle rhythmic pressure intended to stop his death. His eyes looked directly into mine.

Then he was gone.

During the required debrief, some nurses cried and some went home. I remember feeling confused, unsettled. How could they allow themselves to feel so openly? How could they just walk out in the middle of a shift?

I could not feel anything.

Not grief. Not horror. Not even sadness. Only numbness, and perhaps gratitude that I did not need new shoes, and then the urge to keep going without deeper reflection.

As the girl who once passed out in high school health class, I felt confident this numbness was proof that I was becoming a “good doctor.”

It took many years to understand it differently.

These were the early days of disappearing from myself.

Physicians are never explicitly taught to disconnect from their bodies. But we are rewarded for this behavior so consistently that it eventually becomes difficult to recognize as injury. We enter training as healthy, happy young adults and quickly learn to override nearly every internal signal we have. Hunger is denied. Exhaustion is weakness. Emotion is inefficient.

I learned to ignore fatigue, sustained by an occasional quick nap against the microscope eyepiece. Fear and grief were suppressed quickly so they could not interrupt performance. Compartmentalization facilitated survival. At its pinnacle, the performance of the “good doctor” displays as seamless self-denial.

Initially, numbing aligns with success. A surgeon cannot collapse during unexpected hemorrhage. An emergency physician cannot take time to process a prior tragedy before stepping into the next room. Over time, what begins as performance regulation hardens into suppression and denial. Graciously, our bodies adapt to being ignored.

Medical training reinforces this at every turn. “See one, do one, teach one” quietly implies that mastery should come quickly to those worthy of belonging. Struggle should be hidden. Uncertainty is shameful. Rest is negotiated against guilt. Grieving is a luxury we cannot afford. Importantly, all of this unfolds during the years of young adulthood: coupling, uncoupling, raising children, navigating aging parents, accumulating and repaying debt, all while trying to construct identities large enough to hold both ambition and a full human life.

Meanwhile, with reinforcing strength, the healthcare enterprise relies on physicians to navigate all of it with relentless productivity.

For a long time, I interpreted this adaptation as professionalism. So did everyone around me.

A decade later, I sat beside a patient who needed surgery. I remember recognizing fear in his eyes. I felt the familiar instinct to move quickly toward reassurance and solutions, to regain control of the room before uncertainty could fill the space.

This time, something in me paused.

Instead of filling the silence, I simply sat there with him.

Human with human. Space for uncertainty, for both of us.

In that moment, although I could not name it, I felt the full weight of what medicine might actually need from me. Not perfection. Presence.

I called my closest friend, my college roommate. I excitedly shared, “I think I finally understand why this is so hard. We must be perfect at work and then somehow go home and try to be normal people... laundry, homework, dinner... It’s not possible. Doctors struggle because we must be superheroes.”

She was quiet for a moment before answering.

“You don’t need to be perfect,” she said. “You just need to be your imperfect self.”

I remember reflecting on this after we hung up, resisting the idea. She wasn’t medical; she didn’t understand. Maybe I hadn’t chosen the right words to help her see the real issue.

Perfection had been my armor for years. Perfection created distance. Distance allowed performance. If I stopped controlling the room and allowed myself to experience uncertainty, grief, or limitation, what would happen to the version of me medicine had built? Nope. Not me, I concluded. “Good doctors” cannot afford to feel.

At the time, I could not see the reality that perfection was not protection.

Pushing to perfection simply allowed me to ignore the pain of losing my humanity.

Around the same period, I began noticing how deeply medicine admires self-erasure. I sat in physician meetings listening to stories held up as examples of greatness: the off-call physician who left Christmas dinner to save a life; the specialist who kept rounding while his house burned; the boastful normalization of skipping maternity and bereavement leave; the children and spouses passing milestones alone in service to the physician family; the understanding that the needs of the profession superseded everything else. Literally everything and everyone else.

Years earlier, I applauded those stories without hesitation. Witness to our devotion.

Now, I found myself wondering what happens to the people who love us. I wondered when the profession had fused self-abandonment and virtue.

For me, the illusion finally collapsed through personal loss of my three daughters.

The premature birth of my triplets was filled with fear, sepsis, pulmonary edema, hemorrhage, and messy humanity. I remember the glaring lights of the operating room and the relentless sound of monitors I could not control. The impossibly slow passage of time. Counting days to viability. I remember struggling to breathe before surgery while the anesthesiologist placed a mask over my face and told me to take deeper breaths.

“I’m in pulmonary edema,” I cried. “I can’t breathe.”

He looked at me and asked, “Are you some kind of nurse?”

“I’m a doctor,” were my final words before I lost consciousness.

Before I finally lost my ability to control.

Only hours earlier, I had been lying alone in a hospital room, so weak from magnesium toxicity that I could not reach the nurse call button. So thirsty, nothing-by-mouth in case my daughters came early and I required surgery, I managed to walk my fingers to the corner of a washcloth in the washbasin and brought moisture to my lips. In that terror of fear and loss, that dirty washcloth brought incredible comfort.

For years, I had believed being a good doctor required endless self-abandonment. Every patient. Every time. No limits.

But in those moments, stripped of certainty, capability, and control as I lost my daughters, there was no level of preparation, intelligence, discipline, or control capable of guaranteeing safety.

And beneath that realization was something subtler, and much more significant:

Medicine is not better when it requires the destruction of the healer.

Healing does not live solely inside technical mastery or perfectly executed interventions. It also lives in the willingness to remain present in the face of uncertainty, in the ability to sit beside suffering without fleeing, and in staying connected enough to ourselves that we can remain connected to others.

For years, I thought the goal was to feel less. Now I think the goal is to remain human enough to keep feeling it all.

We are not machines practicing on bodies. We practice medicine from within the human condition. One fragile human being holding another through sickness, healing, joy, and loss.

Perhaps the real myth of the “good doctor” is not that physicians must silently endure impossible things. It is that excellence in medicine ever required leaving our humanity behind. ■

Biographical Note

Brooke M. Buckley, MD, MBA, FACS, DipABLM, is a physician executive and maintains a chronic wound care practice at Henry Ford Health. Her work explores physician identity, leadership, human capacity, and the organizational conditions that allow clinicians to remain connected to themselves and others throughout a career in medicine.

THE WAYS HER BODY SPEAKS

Megan H. Pesch, MD, MS

Henry Ford Health System, Detroit, Michigan, United States

pesch@umich.edu

KEYWORDS: Autism; Embodiment; Communication; Mother

I did not understand autistic bodies until one emerged from my own.

Before that, I knew autism the way medicine had taught me to know it: Through diagnostic criteria, developmental histories, rating scales, observations, and concern. I knew how to recognize patterns. I knew how to guide families through referrals, therapies, school supports, and follow-up. I knew autism as a condition to identify.

Then my daughter was born. As I came to know my daughter's personality, and as she grew into herself, gradually weaning, her body separating from mine in the ordinary way toddlers begin to do, I noticed that she inhabited her body differently than my older children had.

Not all at once. There was no single moment of revelation. My learning came in small revisions, the kind that accumulate quietly until you realize the landscape has changed. What I thought I understood receded. What had been hidden inside my assumptions came into view.

A developmental and behavioral pediatrician myself, like most doctors, I was trained to read bodies quickly. We notice eye contact, posture, tone, movement, facial expression, gait, stillness, agitation. We translate what we see into meaning: anxious, comfortable, delayed, dysregulated, cooperative, in pain. Often, this helps us provide care. But interpretation is never neutral. It is shaped by what kinds of bodies we expect to encounter and what forms of communication we have been taught to recognize.

My daughter taught me that some bodies speak in ways medicine does not always hear.

She moved before she had words for why she moved. She recoiled before she could explain what felt unbearable. She sought pressure, rhythm, repetition, retreat. She could be undone by a seam in her ruffled ankle sock. Ten minutes of sitting in my lap, being hugged tightly could give her day back. There were days when joy moved through her body so visibly it seemed to spill from her fingertips. When exploring the sandbox with her hands buried deep in the grains brought about unimaginable thrills.

I loved her before I understood any of it. Love came easily. Understanding took longer.

There is a particular humility in being taught by your child. This learning required me to set aside habits that had once felt useful - the reflex to interpret movement as behavior, refusal as opposition, repetition as symptom, silence as absence.

What if pacing is regulation rather than avoidance? What if looking away reflects pain rather than defiance? What if a body in motion is not disordered, but adapting intelligently to an environment that asks too much of it?

Medicine often privileges certain kinds of bodies: Bodies that sit still, tolerate fluorescent lights, accept touch without much warning, answer quickly, modulate tone, make eye contact on cue, wait patiently, ignore smells, and perform calm. These expectations can feel invisible because they are so familiar. But they are not neutral standards of health. They are norms. When a child cannot meet them, we often locate the problem in the child.

I did this too, even when I believed I was being compassionate.

In clinic, I have started to notice autistic children differently. The child circling the room might be organizing an overwhelmed nervous system. The teenager who could not answer my question might need time measured in minutes, not seconds. The patient resisting an examination might not lack cooperation, but trust. The parent describing a meltdown might be describing a body pushed past its capacity to cope.

Nothing about these children had changed. What changed was the lens I brought to them.

This matters because misreading bodies has consequences. Pain can be overlooked. Distress can be mislabeled as aggression. Communication can be mistaken for noncompliance. Necessary procedures can become traumatic. Families can leave feeling blamed rather than helped. Patients can learn that healthcare is a place where they are managed, not understood.

Too often, we ask patients to conform to the conditions of our clinics and then interpret their difficulty doing so as pathology. Caring well requires something else: humility about our assumptions, curiosity about embodied difference, and a willingness to build clinical spaces where more people can be safely understood.

My daughter also taught me something gentler. Autistic embodiment is not only struggle. It is pleasure too: delight in pattern, deep sensory joy, full-bodied laughter, the steadying comfort of repetition, fierce honesty, intense love. To write only of burden would be another kind of misreading.

There are still moments when I do not understand my daughter's experience. I am her mother, not her mirror. Love does not erase difference. But love has made me slower to assume and quicker to ask. It has taught me that understanding is not a prerequisite for respect.

I think often now about how many patients I met before I knew how little I knew. How many bodies I translated too quickly into categories that made sense to me, but not to them. My daughter did not simply change my understanding of autism. She changed my understanding of medicine. ■

Biographical Note

Megan H. Pesch, MD, MS, is a developmental and behavioral pediatrician and physician-scientist whose clinical and research work focuses on autism, neurodevelopment, and childhood hearing differences. She is the Director of the Center for Autism and Developmental Disabilities at Henry Ford Health System, and cares for children with developmental differences and their families. Her work is informed not only by her clinical and research experience, but also by her experience as the mother of a child with hearing differences, and autism. This intersection of physician, researcher, and parent has shaped her interest in how medicine understands disability, communicates uncertainty, and learns to listen to the lived experiences of children and families.

THE CELLAR HELD: KNILL'S MAGIC UNDERWORLD AND THE PRACTICE OF WHOLE PERSON CARE

Richard Wainwright

Research Director, Vancouver Art Therapy Institute, Vancouver, British Columbia, Canada
Adjunct professor, European Graduate School, Saas-Fee, Switzerland
richard.wainwright@vati.bc.ca

KEYWORDS: Whole person care; Paolo J. Knill; Expressive arts therapy; Underworlding; Decentering; Shelter-play; Arts-based inquiry

A *hospital room with too much light.*
A chair placed too far from the bed.

A child watching adults speak above them.

A gathered family that tries to not let life-supporting machines define the scale of these final encounters.

A therapist that reaches too quickly for interpretation because silence has become hard to bear.

Paolo J. Knill gives this problem a cellar.

Knill was a Swiss artist and therapist, one of the founding figures of Expressive Arts Therapy. Alongside Ellen G. Levine and Stephen K. Levine, he helped articulate an intermodal approach in which the arts move across image, sound, movement, and story (Knill et al., 2005). His work stays close to practice. Materials are not treated as illustrations of an idea. They are part of the event. A floor, a puppet, a drumbeat: such things alter the conditions of experience.

In "Communal Art-Making and Conflict Transformation," Knill (2011) recalls his childhood during World War II on Swiss territory near the German side of the Rhine. The geography is already divided. Adults around him live with military preparation and the fear of bombardment, near a border where war is never abstract. Children absorb this atmosphere without being given much language for it. Then the alarms come and bodies move below ground filling the shelter. Children huddle and wonder whether the impact has already happened.

The cellar is first organized by danger.

Then the children begin to alter it.



Figure 1: *Magic Underworld above the town.* Richard Wainwright, 2026.

Knill remembers children painting the walls and carpeting the floors, carrying toys and puppets underground, inventing roles and stories, and guarding the entrance with a shared password, sustaining the play from one alarm to the next (Knill, 2011). The Magic Underworld becomes so compelling that, by 1944, the children spent more time there than outside. A shelter made for survival becomes a *made* world. It is still beneath war, just as it is inside fear. The children have worked on the world around them.

Painted walls.

Carpeted floor.

Puppets.

Vehicles.

Pastels.

Password.

Story.

The sequence is small, almost domestic, and that is where its force sits. The children cannot repair the adult political world, yet they can bring things down by hand. They can alter a surface, create and repeat a story, and become characters together beneath the sound of war.

The cellar does not end fear. It gives fear somewhere else to go.

Here the widened mandate of Whole Person Care and Knill's intermodal Expressive Arts Therapy begin to touch. Whole Person Care names the need to attend to suffering as lived experience, not only as disease that is treated. Expressive Arts Therapy names a way of entering experience through form, rhythm, and relation. Both resist the illusion that help always begins with explanation. Both know that suffering may need a room before it can bear a sentence.

Expressive Arts Therapy names one movement inside this order as decentering. In Knill's intermodal tradition, a person or group may step away from the tightened grip of the problem and enter another field of action through artistic practice (Knill et al., 2005). Though the difficulty is still present, its terms shift through material, tempo, and relation. Knill later calls this an "alternative experience of worlding" (2011, p. 55). The phrase reinforces that art is not being used as an escape hatch, but rather to compose another experience inside the world that remains.

The children in the Magic Underworld do this before any theory explains it. By making conditions under which they can keep living inside its interruptions they create an underworld, opening a second order below the first one. The alarm still breaks ordinary time, and the adult world still fails to protect them from fear. And yet, stories and friendships continue. They regain power.

I use *underworlding* as nomenclature for this temporary making of aesthetic shelter beneath conditions that exceed repair. For me, the term must stay tied to Knill. The Magic Underworld is his memory, his childhood account of a communal aesthetic practice formed under wartime conditions. Underworlding, as I use it here, extends from that image into Whole Person Care. It names the careful making of a smaller world inside a larger situation that cannot yet be changed.

The process of underworlding is all around us, and it requires our attention and awareness to notice. Consider a seven-year-old on a surgical ward the evening before an operation. She lines three animal figures along the edge of her blanket, names the largest one the surgeon, and gives it a gruff voice while the smaller two hide under a fold of fabric. The child's counselor sits nearby and does not ask what the game means. Over twenty minutes the fold becomes a mountain, then a hospital, then a cave with a password at its entrance. Nothing about the morning's surgery changes. The child's relation to it does. She has rehearsed entry and exit at her own tempo, with materials she can command, beside an adult who lets the world stay hers.

Underworlding is fantasy with flooring.

Concepts like Whole Person Care can become abstract and require such grounding. A care plan can record that spiritual needs were addressed while no one has yet sat beside the bed. A ward round can list the family as a support system without asking who is afraid to enter the room. Knill's cellar provides necessary resistance. Here, context is not a vague surround. It is a place with surfaces, shared rules, and carried objects. A room first shaped by war is reshaped by children. The change is modest, but care often depends on modest acts: a chair moved closer, a light softened, a practitioner choosing silence before explanation.

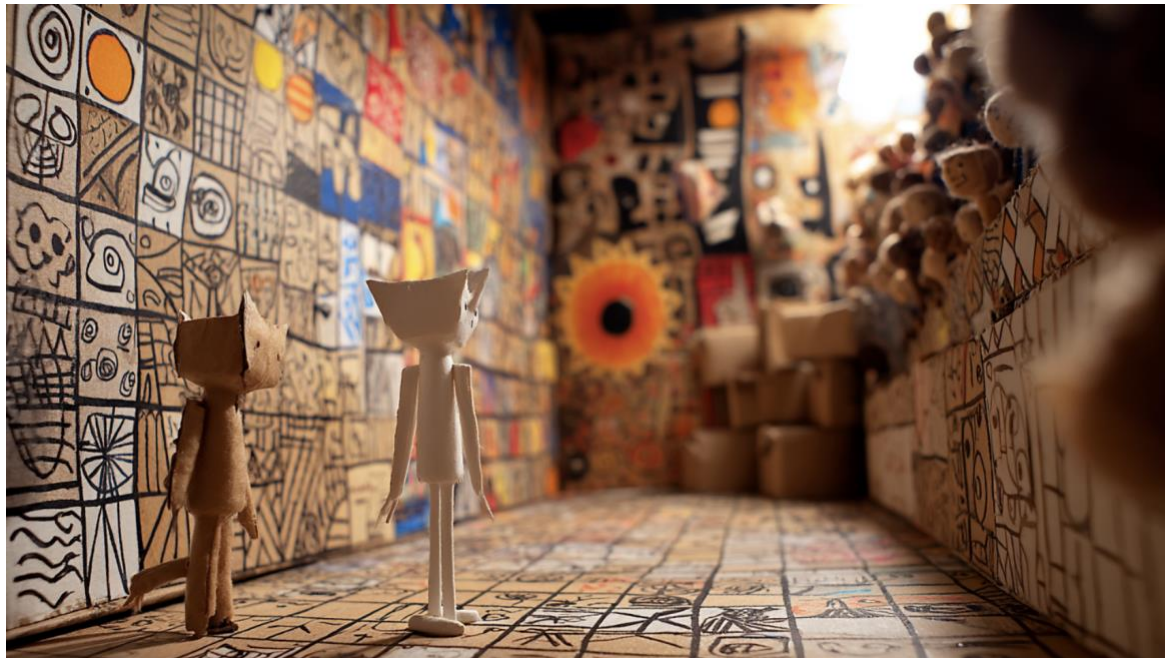


Figure 2: *Magic Underworld below the town.* Richard Wainwright, 2026.

Suffering is carried in bodies before it becomes narrative. It shows in a held breath when footsteps stop outside the door, in a startle after the alarm, in the fatigue of waiting for news. Knill's account stays close to this bodily field. The children crouch and listen; then they paint, carry, and return. Their bodies are frightened and busy at once, the materials allow them to enter the space differently.

Knill remembers the shelter as collective. Each child likely carried a private world into the cellar, a favoured toy, a preferred role, an image no one else could see, yet those private worlds took shape inside a shared one. Passwords, roles, and repeated returns produce a small social order under a damaged one. Whole Person Care has to hold that scale too. A person suffers, and communities suffer with, and sometimes because of, that person. Care is never only individual, even when the patient lies alone in the bed. Someone has arranged the room. Someone is waiting outside. Someone has already been changed by what illness has done to the group.

My own work in arts-based inquiry has circled this claim from another side: making is more than the expression of an inner state. It is a distributed encounter among bodies, materials, and institutions (Wainwright, 2022). Knill's shelter can be read through that lens. The children are expressing fear, yes, but they are also assembling a world with walls, alarms, absent fathers, and one another. The puppet participates. The alarm participates. The cellar participates through what it allows and what it restricts.

This distributed view changes how care can be imagined. When suffering is located only inside the individual, care moves too quickly toward interpretation, adjustment, or correction. When suffering is also carried by rooms, routines, and institutional timings, care can begin by altering the field. Move the chair. Lower the noise. Keep the song. Let the patient hold the photograph without demanding a story from it. Let the child play before asking for feelings. Let the family repeat the ritual even when the chart has no place for it.

Stephen K. Levine's writing on trauma, tragedy, and therapy helps hold the same line. The arts do not promise to erase human suffering. They may give form where experience has become too large, too chaotic, or too saturated with fear (Levine, 2009). A line, a movement, or an image gives the person and the group a way to stay near what cannot yet be solved without being consumed by it.

Aesthetic restraint belongs here. A child's puppet play should not be hurried toward diagnostic meaning. A drawing should not be seized as evidence. A bedside song should not need to become an outcome measure before it counts as care. In Expressive Arts Therapy, aesthetic response attends to what is happening in the work: where an image gathers density, what material resists, what becomes possible after making. The practitioner does not need to translate everything into clinical language at once. Sometimes the most careful act is to hold the made space long enough for another relation to the difficulty to appear.

The Magic Underworld also demands ethical caution. The scene can become too charming if handled badly. The story almost invites sentimental reading, and that invitation has to be refused without stripping the memory of its tenderness. The cellar exists because the world above has failed the children. Their play is

extraordinary because the danger is real. The aesthetic force of the underworld cannot be used to soften the violence that made it necessary.

I have made a related argument with Shannon Stevens in writing about aesthetic seduction and scenes of harm (Stevens & Wainwright, 2020). Images, stories, and artistic forms can draw viewers into admiration at the wrong scale. They can make damage feel resolved because it has become formally compelling. Knill's memory needs a similar care. The painted cellar is not redemption. The children were still under bombardment. The underworld is a fragile practice of relation under conditions no child should have to aestheticize in order to endure.

That ethical tension keeps underworlding from becoming resilience talk. Resilience is too often used to praise people for surviving arrangements that should have been changed. Knill's children made a world, and the need for that world remains an indictment of the world above. Whole Person Care needs room for both claims. A healing space can be made under frightening conditions. The making of that space does not absolve the larger structure that made the space necessary.

Consider a palliative room where a man in his last weeks can no longer follow conversation. His daughter brings the small radio from his workshop and tunes it low to the station he kept on while repairing clocks. A nurse shifts the intravenous pole so the bedside table can hold the radio, two photographs, and his reading glasses. Visitors begin to stay longer. The room now has his sound in it. No symptom score records the change, and the dying continues, yet the man appears as a person with a workshop, a station, and a habit of tinkering. The disease no longer takes up the whole room. This can be seen in grief work that conjures images before speech has the capacity to express it, or in communal cooking or in the noticing and honoring of exhaustion and how a helper might choose to enter a room quietly.

Recent writing on creativity, play, and the future of Expressive Arts Therapy carries this same concern. Tatjana Jansen and I have argued that arts-based healing practices are often pushed aside when care narrows into technique, intervention, and measurable output (Jansen & Wainwright, 2025). Knill's wartime memory moves in the opposite direction. Play becomes a condition of survivable relation, the cellar a place where the children can continue as children, together, under conditions arranged by adults, armies, borders, and bombs.

Whole Person Care cannot replace medicine with art. Medicine, clinical judgment, and skilled treatment remain necessary. The arts allow suffering to be approached through form, tempo, and shared attention, and they protect the person from being overtranslated. They make space for what cannot arrive as direct statement.

The practitioner is part of that space. Physicians, nurses, Expressive Arts therapists, and community workers all enter with bodies that shape the room. They notice or fail to notice. They rush or wait. They can turn care into procedure, or they can protect a small practice from being crushed by it. A child's game, a family's song, or a drawing that does not yet want interpretation can each need that protection.

An existential and spiritual dimension runs through the scene, though no formal religious language is required. The children are living questions that Whole Person Care knows well. What kind of world can be made when the given world has become unsafe? Who can be trusted below when the adults above are divided? What can fear become once it is handled, repeated, and shared? The cellar answers through practice.

A wall takes colour.

A floor takes carpet.

A puppet takes motion.

A group takes a password.

Care often begins this way, before the sentence forms. Someone makes room and allows time. Someone places materials within reach and protects a repeated gesture. Someone lets a child invent, a family sing, a practitioner pause. The whole person appears through these arrangements: bodily, relational, spiritual, and still situated inside conditions that may not change.

Underworlding names the small construction of care where the larger world cannot yet be altered. The memory is too specific to become a universal model; it offers a pattern of attention. When the world above has become too dangerous, too clinical, too saturated with explanation, a smaller world may still be made with care.

At the end of Knill's account, nothing resembles triumph. What remains is the memory of the play, the friendships across adult divisions, the password that continued, and the sadness when the Magic Underworld was over (Knill, 2011). That sadness belongs inside the theory. Healing spaces are often temporary. They are made because something has already been threatened or lost. Their force lies partly in that fragility.

Whole Person Care begins again there, in the making of a space where a person and communities may still appear: bodily, relational, mortal, and alive to others.

Beneath the war, the children made a world.

The cellar held.

References

1. Hutchinson, T. A. (Ed.). (2011). *Whole person care: A new paradigm for the 21st century*. Springer.
2. Jansen, T., & Wainwright, R. (2025). The wild beyond: Creativity, play, and the future of expressive arts therapy. *Routledge Open Research*, 4, Article 2. <https://doi.org/10.12688/routledgeopenres.18774.1>
3. Knill, P. J. (2011). Communal art-making and conflict transformation. In E. G. Levine and S. K. Levine (Eds.), *Art in action: Expressive arts therapy and social change* (pp. 53–77). Jessica Kingsley Publishers.
4. Knill, P. J., Levine, E. G., & Levine, S. K. (2005). *Principles and practice of expressive arts therapy: Toward a therapeutic aesthetics*. Jessica Kingsley Publishers.
5. Levine, S. K. (2009). *Trauma, tragedy, therapy: The arts and human suffering*. Jessica Kingsley Publishers.
6. McGill Programs in Whole Person Care. (n.d.). *Whole Person Care*. McGill University. Retrieved April 29, 2026, from <https://www.mcgill.ca/wholepersoncare/>
7. Stevens, S., & Wainwright, R. (2020). A review of *The Anthropocene Project: Treachery in images*. *Art/Research International: A Transdisciplinary Journal*, 5(2), 567–584. <https://doi.org/10.18432/ari29496>
8. Wainwright, R. (2022). *Ontological play: Reinventing (machinic) arts-based research in the posthuman era* [Doctoral dissertation, University of Victoria].

AI statement

OpenAI's ChatGPT was used for smoothing and grammar. The composition, content, images, interpretation, and final decisions are the original work of the author.

Biographical Note

Richard Wainwright is Research Director at the Vancouver Art Therapy Institute and an adjunct professor at the European Graduate School where he teaches and supervises graduate research in Expressive Arts Therapy, arts-based inquiry, and creative arts therapies. Across teaching, supervision, and research, he

The Cellar Held: Knill's Magic Underworld and the Practice of Whole Person Care
Richard Wainwright

explores how artistic practice can help people stay with illness, uncertainty, grief, and meaning-making in ways that honour the whole person.

EMBODIMENT IS MEDICINE: RECLAIMING THE NON-VERBAL INTELLIGENCE OF THE BODY IN MODERN MEDICINE

Marina Heron Tsaplina

Founder, Your Body is Medicine

hello@yourbodyismedicine.com

KEYWORDS: Embodiment; Healing, Somatics; Medical education; Embodied training

The Silencing of the Communicative Body

I used to describe medicine's habit of silencing the intelligence of the body as a 'disembodied crisis'. While I find this description to be an accurate diagnosis, did you notice what happens to your body and perception when you read those words? Take a moment to slowly speak 'disembodied crisis' out loud a few times. Notice how your body responds. What happens to your breath, body and feeling as you voice those words? Speak, pause and listen to your interiority. For me, the first thing I noticed was how this description gathered my internal energy - my awareness - behind my forehead into a sharp focus-point directed outwards. To the place of cognitive focus and intellectual analysis.

Cognitive analysis is the mode of knowledge prioritized by modern Western medicine (biomedicine) [1] and medical education. Naming biomedicine is important, as the silencing of the intelligence of the speaking body is a cultural habit that is unique to this specific lineage of medicine and science [2, 3]. French physiologist Claude Bernard, who is widely regarded as the 'founder of modern medicine' [4] described his vision for physiology in 1878 [5] as such:

"By the physico-chemical sciences, man proceeds to the conquest of brute nature, of dead nature: all the earth sciences [...] are nothing other than the rational exercise of the domination of man over the world. In this, is physiology like the other sciences? Can science which studies the phenomena of life pretend to master them? Does it [physiology] intend to subjugate living [human] nature as dead [non-human] nature has been subjected? We do not hesitate to answer in the affirmative. Physiology must therefore be an active and conquering science in the manner of physics and chemistry."

Let us pause and breathe so that the violent winds of subjugation of both people and planet carried by these words subside. I am quoting these words to make visible that the silencing of the speaking, intelligent body is in the origin seed of what became the biomedical tradition.

Letting Go of a Harmful Habit

The connective tissue between Claude Bernard's philosophical imagination of 'subjugating nature' and contemporary medicine's habit of silencing the communicative body is the domination by cognitive analysis over other forms of intelligence.

This is because the body's intelligence cannot be *experienced* analytically and thus remains obscured. Becoming attuned to how the body speaks requires a different mode of listening.

Disease and the body being taught as mechanical, medical objects [6] that can be controlled is a symptom of this same habit and imagination. When a clinician describes "controlling" my Type 1 diabetes, I hear echoes of this lineage. I know it is unintended, and not the speakers' fault. Culture, practices and habits are all inherited. They become embodied habits (or in this case, disembodied habits), shaping how we touch, see, perceive and act.

Yet the intelligence of the body can never fully be subjugated. Neither can disease nor illness. After a lifetime of living with/against/despite/alongside Type 1 diabetes, my body has let me know, repeatedly, that control is an illusion. My chronically brilliant body (the language I prefer in place of "chronically ill") is a wild river, perhaps an oceanic sea. I steer my ship the best I can and do my best to not awaken storms. Being told to control (or conquer, in Bernard's words) these waters led me to a volcanic eruption of jest and a quoting of Hamlet: "There are more things in heaven and earth, Horatio [Bernard], than are dreamt of in your philosophy."

Remembering the Body's Intelligence

Qi is one name for the intelligence of the body from the Tradition of East Asian Medicine. In Acupuncture, there is nothing special about the needles that are used: it's not the needles that are the medicine. The work is done by your *Qi*, or life-force. The medicine in Acupuncture is your own body's intelligence finding a new conversation within your system, stimulated by the needle placements.

Qi can be described as the subtle energy of the body. It is not reducible only to biological function, which is where the gap with the biomedical canon emerges. Qi Gong [7], which I practice and incorporate into my teaching of embodiment, is about stabilizing your *Qi*. Both practices evolved from the understanding that it is the body's own intelligence that is the medicine. When I describe my body as a wild river that I can steer but not control, I am acknowledging -- with reverence and humility -- its agency, intelligence and will. It is this wisdom that Bernard's philosophy seems to have forgotten, for to believe that the body and disease can be conquered is to deny the body's deeper intelligence, personhood and relational autonomy [8].

When I spoke the words "disembodied crisis" out loud and listened for my body's response, there was also an alertness and a faint but present bracing vigilance that arose in my head and chest. My breath tightened. At the same time, a kind of hollowed out cavity behind my heart opened. I can recognize that this cavity holds the traces in my nervous system of deeply imprinted feelings of loss, depletion, and grief.

Embodied healing does not mean that such traces are completely erased, or "cured." I honor the memory my body holds at the cellular level [9]. Rather, healing means I am no longer overwhelmed and taken over by these nervous system states. This is what "stabilizing *Qi*" means - though there are other ways to express this. I can notice, observe and acknowledge these bodily states, because I have allowed myself to feel them, receive their lessons and communication. The stabilization that emerges from deep embodied healing leads to developing the capacity to remain grounded in one's 'center self' through the waves of life.

Embodiment is a Practice of Listening to the Worlds Beneath Words

This kind of embodied attunement is a practice. It is a skillset that can be trained over time. This is my 16th year of working with the intelligence of my body, and my 10th year of teaching embodiment in medicine to patient, student and clinician communities. Before I could teach it, I was brought to my knees in surrender. This is how my learning of embodiment began: a spiritual crisis that opened a floodgate. The wisdom of my own life-long chronically brilliant body, and all "it" had to say, would no longer remain silenced. [10]

Words carry worlds. Those worlds are made of embodied memories and sensations that are unique to each of our life-paths, traumas, ancestries, and more. Disease, illness, disability is never isolated from this greater tapestry - it becomes interwoven into these threads, shaping and being shaped by them. This is

why the same illness may awaken distinctly unique existential territories within different people. My childhood Type 1 diabetes diagnosis was interwoven with familial developmental trauma, contributing to a deeply fractured sense of self-worth. Embodiment asks us to embrace the messy knots of our body-mind-spirits, untangling each thread slowly, over time. This inner work, while by no means easy, is the work of inner freedom that then moves outwards to every person you encounter. It is directly connected to freeing the subtle energy of your body.

Given the distinct life fabrics of each one of us, “disembodied crisis” may have opened a different pattern of affective states and sensations in your own body. (The language of “disembodied crisis” awakening cognitive analysis and bodily defense is also why I now instead use the description of *medicine's habit of silencing the body's wisdom*. Notice how differently that feels in your body!)

What *worlds* do those body-states hold? This question matters greatly in the secret chambers of embodied healing.

Learning the Language of the Communicative Body

As the body's intelligence cannot be perceived analytically, embodiment training is experiential. Carefully designed exercises and practices bring the practitioner into direct experience of their bodily communication. The body's intelligence communicates through breath, rhythm, feeling, sensation, imagination and embodied imagery.

In response to the mechanistic approach to the body and disease, I developed a training curriculum for medical students and seasoned clinicians in embodiment. It is common for students to ask, “why are we focusing on our own bodies? It's about our patients.” The answer is deceptively simple: you can guide your patients to listen to the intelligence of their bodies only when you have learned how to listen to your own.

My training curriculum is designed to open access in the practitioner to these modes of the body's communication. To offer a vivid example, [*this 3-minute video](#) has the voices of students describing their experiences. Remember how words carry embodied worlds? This video documents embodied exercises that make the meaning of that sentence tangible through direct experience.

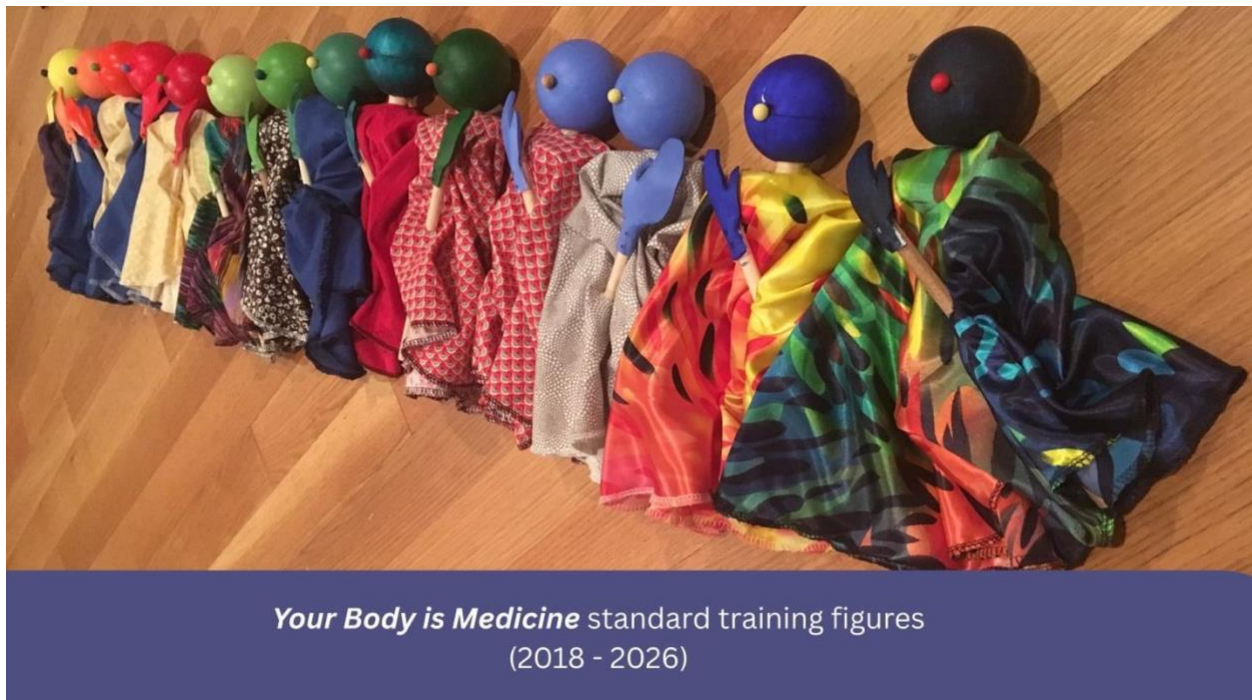
I invite you to pause reading and watch the video before going further. These exercises lead each student to experience how emotion and imagery lives in connection to their bodies. How their breaths and bodies carry meaning, emotion and memory. Students are shown working with *training figures*. The audio is student voices describing the places in the body where each felt imagery and sensation arise, in response to a specific word they chose. Notice how this is also a practice of embodied community and teamwork.

The training figures share one similarity in their role to the needles in acupuncture: *it is not about the object*. It is about what working with these objects gives you access to in your bodily intelligence.

This training changes *how* listening is enacted by the practitioner, it expands what is perceived and what information is deemed relevant. Importantly, the training method itself is embodied. This means learning how to listen to, from, and *through* your communicative body. This shift alone can take many sessions.

The cognitive muscle is so habituated and overtrained, it takes many people time to allow themselves to listen, work and even play from the non-cognitive/analytic parts of themselves (I am side-stepping discussions on the nature of consciousness, embodied cognition, etc. in this short text!) Playfulness is an important component of the training. It builds the capacity for nervous system states to no longer grip and overpower the person, strengthening and stabilizing the 'center self.'

* <https://vimeo.com/279149660/d3f9b9bca8?share=copy&fl=sv&fe=ci>



New Training Paths to Reconnect with The Body's Intelligence

I am aware how different this training is from learning about the biological mechanisms of disease from a textbook, being expected to fulfill checkboxes, or even reading patient narratives. I want to be clear that each of the prior-listed methods are important and necessary. At the same time, learning how to perceive and work with the non-verbal intelligence and communication of the body requires a different approach than

what medical education, continuing medical education, and even the medical/health humanities currently practice.

Illness very often disrupts the sense of trust between person and body. The felt-sense of embodied trust, of being home in one's body [11], can only be reconstituted through embodied practice. Without this, healing – regardless of illness or disability status – is impossible.

In collaboration with a leading physician of compassionate care, we interviewed three cohorts of students two, three, and four-years post-training. Many were completing medical school or in residency. They described concrete impacts in how they practice medicine, in how they listen to and touch patients' bodies. Following this, we began bringing this work to seasoned clinicians.

The body's communicative brilliance cannot be accessed nor supported when doctors, nurses, and people in the healing professions are trained to perceive, think and listen only analytically, are embedded in a culture and system that rewards and applauds their disembodiment, and furthermore largely dismisses the mysterious, non-linear and largely non-verbal languages that are part of the body's foundational intelligence. It is only when cognitive brilliance is brought in service to this deeper intelligence that holistic, embodied care and true healing emerge.

The Body's Intelligence is the Foundation of Medicine

The medicine of insulin grants me access to life. Learning how to listen to and *trust* the intelligence of my body is the medicine that allowed me to heal (while still taking my insulin). The two co-exist on an equal playing field, without hierarchy. Notice how I am purposefully expanding the definition of what constitutes medicine. I am not describing the intelligence of the body as “complementary” to insulin or other biomedical interventions. I am asserting that without acknowledging and knowing how to support, respond to and guide the body's inner intelligence and communication, biomedical intervention can become a form of assault.

I believe we are finally at the beginning of this return to the body. Biomedicine 'reclaiming' the body as a knowing, communicative, and relational participant in care and healing will be a quiet revolution that transforms the practice of modern Western medicine from the inside out. It will happen slowly and steadily, as practitioner by practitioner begin to quietly acknowledge and train in how to listen to their own bodies.

When healers allow themselves, and are allowed, to heal (by being institutionally and culturally supported to do so), they can become supportive guides for the healing paths of the people they serve. This will restore the body's intelligence to its rightful place: as the foundation of medicine in all medical traditions.

Dear clinicians and patients: your body *is* medicine. ■

REFERENCES

1. Wiseman N. Designations of Medicines. *Evid Based Complement Alternat Med*. 2004;1(3):327-329. <https://doi.org/10.1093/ecam/neh053>
2. Luce Communications. "We Need to Blend Indigenous Knowledge and Western Science for Deeper Insights," say Indigenous Scholars. Henry Luce Foundation. 2024 Sep 19. Available at: <https://hluce.org/we-need-to-blend-indigenous-knowledge-and-western-science-for-deeper-insights/>
3. Despret V. The Body We Care for: Figures of Anthro-zoo-genesis. *Body & Society*. 2004;10(2-3), 111-134. <https://doi.org/10.1177/1357034X04042938>
4. Habert R. Claude Bernard, the Founder of Modern Medicine. *Cells*. 2022;11(10):1702. <https://doi.org/10.3390/cells11101702>
5. Cohen E. A Body Worth Defending: Immunity, Biopolitics, and the Apotheosis of the Modern Body. Durham: Duke University Press; 2009. doi: 10.2307/j.ctv121028v
6. Good BJ. How medicine constructs its objects. In: *Medicine, Rationality, and Experience: An Anthropological Perspective*. Cambridge: Cambridge University Press; 1994. p. 65-87.
7. National Center for Complementary and Integrative Health (NCCIH). Qigong: What You Need to Know. U.S. Department of Health and Human Services, 2022. Available at: <https://www.nccih.nih.gov/health/qigong-what-you-need-to-know>
8. Graham M, Brigg M. Indigenous international relations: Old peoples and new pragmatism. *Australian Journal of International Affairs*. 2023;77(6):590-599. <https://doi.org/10.1080/10357718.2023.2265847>
9. Popular Mechanics. Do our Memory Cells Hold a Form of Consciousness? 2026. Available at: <https://www.popularmechanics.com/science/a70578341/memory-cells-consciousness/>
10. Tsaplina M. Bodies speaking: Embodiment, illness and the poetic materiality of puppetry/object practice. *Journal of Applied Arts & Health*. 2020;11(1-2):85-102. https://doi.org/10.1386/jaah_00020_1
11. Awdish R. *After Shock: Learning to Reinhabit My Body After Illness*. New York: St. Martin's Press; 2026.

Biographical Note

Marina 'Heron' Tsaplina is a NYC-based award-winning artist, writer, teacher and scholar in medical humanities. Her work centers the intelligence of the body within medicine, disability, and environmental healing. She holds a Master's in Bioethics and Medical Humanities and is a certified Somatic Developmental Trauma Therapy Coach. Her embodied training program, Your Body is Medicine, was developed during her time as a Kienle Scholar in the Medical Humanities at the Penn State College of Medicine, as co-founder of the Reimagine Medicine program at Duke University, through a residency with the Philadelphia College of Osteopathic Medicine, and by working with over 600 patients, students and clinicians. From 2024 - 2026, she was an Artist in Residence with Dr. Rana Awdish at Henry Ford Health to bring Your Body is Medicine to seasoned clinicians. She loves translating between the worlds of art and science, and helping doctors to trust the profound mystery and knowledge of their own bodies in service to their patients.

THE BREATH BEFORE THE CUT: A RESIDENT'S PERSPECTIVE ON SURGERY, MUSIC, AND THE BODY

Sarah Klapman

Queen's University, Kingston, Ontario, Canada

sarah.klapman@KingstonHSC.ca

KEYWORDS: Surgery; Surgical training; Music; Opera; Embodiment; Anxiety; Mindfulness; Narrative medicine

My father's hands are in my earliest memories. As a pianist, his left hand is wider than his right, stretched by years of playing stride – a genre requiring a very broad reach across the lowest notes. I was always mesmerized by the way his fingers flew across the keys, shaping sound and time. I wondered if my own hands would ever fly.

My mother would be there too, his lifelong duet partner, singing along and organizing the sheet music and just generally making the whole thing work. She would put her hand on my shoulder while I hovered nearby, peering over the piano lid. Her touch has always been warm.

Years later, when I first found myself in an operating room, sawing through the leg of someone I had just met, I found myself again thinking of my father's hands, my mother's touch. There is a flashbulb moment in your first surgery: when scalpel meets skin, you learn instantly whether the OR is for you. I was convinced I would faint and, being 6'2", was worried I would knock over the scrub nurses like bowling pins. To my surprise, the cut deepened, and the blood welled, and I was fine. And – because I'm a first-born daughter – I decided to do the hardest thing I could think of. I would be a surgeon.

As it turns out, the process of surgical residency has been even harder than I expected. Hugely rewarding, sure, deeply satisfying and immensely gratifying, but often so challenging that it leaves no breathing room

for life. Unlike music, I wasn't raised living and breathing surgery. (My father was initially disappointed I had chosen medicine at all – "But honey, you're so talented!" – the only parent upset at a med school acceptance letter.) And while the cognitive aspects of learning surgery have been difficult, the physical experience of operating has been just as hard.

In the years before medical school, I planned to be a professional musician. I studied classical voice and had big dreams for life as an opera singer like my mother. But over the course of my voice degree, I became intimately familiar with the mind-body connection. Stress shuts down the voice faster than almost anything else: the minute muscles of the larynx and pharynx lock, thyroarytenoids, cricothyroids, all interconnect with the fine muscles of the neck, the bulk and breadth of the shoulders, the long lines of the back. When one tightens, they all tighten. The anxiety I felt as a music student translated itself directly to my voice, and over the years of my degree, when I couldn't seem to figure out how to make my body loosen, I fell out of love with singing. The piano in my childhood living room felt very far away.

I moved into research and did a master's degree in music and dementia, wanting to be close to music but needing to approach it from a different perspective. My grad school experience taught me I wanted more face time with patients, and I pivoted to medicine, which was how I found myself assisting in the below-knee amputation that sealed the deal on my surgery career. The operating room and the opera stage share more than you'd think: a high-intensity environment, complex teamwork, the ability to change someone's world in real time. And that's not even including the performativity of both spaces. Surgery is a series of auditions. Impressing your attendings is a full song and dance that doesn't end until graduation.

So it came as no surprise that my body reacted the same way to surgical residency as to music school: by locking up. Early in the clerkship portion of medical school, after I'd sailed through the amputation, I fainted in the OR as we removed a woman's breast cancer – a much less gory, less physically demanding operation. I'd forgotten to breathe as I held the retractors. Fortunately, no nurses were bowled over.

The pattern continued: I would walk into the OR, feel my heart start to race, suddenly get flushed and fuzzy-headed and shaky, and realize I was both ravenous and too nauseated to think about food. Every time I scrubbed in, I was convinced I'd go down. Although it never happened again, that anxiety blocked out all thoughts of the case, of learning the anatomy or the operative steps or anything beyond taking one breath after another.

I'm still not completely sure why I stuck to my plan of becoming a surgeon when going to the OR felt like entering a gladiator ring against my own body. I never told anyone – not teachers, not peers, not the rare resident I encountered as a regional campus student. It felt embarrassing, shameful. I wasn't going to show weakness. I'd chased myself out of music, and I wasn't going to do the same with surgery.

There was so much beauty in my medical school experience. I made lifelong friends, learned a completely new way of understanding the world through the biomedical sciences, and encountered innumerable opportunities to contribute meaningfully to my community. I feel deep gratitude for the privilege of medical training. But it has its costs for everyone.

The turning point came one day during a Whipple surgery. While it may seem impossible, I trained at a community site where a single general surgeon had been grandfathered into doing hepatobiliary surgery, otherwise the exclusive purview of major academic centres. Dr. Husien is a soft-spoken, affable, kind-hearted attending and an absolute beast in the OR. He performs these kinds of massive operations like they're nothing. The lack of drama and fuss made it easier to relax around him, and he never yelled when we got questions wrong.

I was standing in the OR as we performed a Whipple, a procedure removing the patient's duodenal cancer, which could easily go for five or six hours (including a delightful snack break). I was engaged and trying my best to help – I'd reviewed the anatomy, watched YouTube videos, tried to understand the steps. Still, as his hands flew, there was only so much I could do. In the quiet space he made, I thought of the piano. For the first time, I considered the memory of those childhood sing-alongs without frustration or hurt. I remembered how I had felt, the warmth, the touch. I felt my shoulders lower, and then drop; I hadn't realized I'd been holding them around my ears. My breathing slowed, the way you inhale deliberately, carefully, to set up the first phrase in a song. I felt my mum giving me a hug from behind, like I could soften and lean back against her. And I was safe.

That OR was a turning point in my surgical training. I still grapple with anxiety, not improved by the fact that, as a musician, I'm often trying to play catch-up on my basic scientific and medical knowledge as compared with my peers. But the feeling of that hug, of being held, has made operating possible. Most of the time it's even fun.

I met my wife during my first year of General Surgery residency. Without this training program, our paths probably wouldn't have crossed, so I have yet another reason for gratitude in this career. Now it's her hug I pull around me when a case gets challenging, when I feel my heartbeat climbing in my ears and my hands start to shake. It's the same feeling I try to share with my Queer patients when I name drop her. I see the shoulders drop, the fine trembles slow. That quiet comfort didn't come from pushing through, from trying to muscle my way into a life that doesn't quite fit. It's been a deliberate series of choices to trust that I'm where I belong. As I advance in training and start taking ownership of cases, each OR is an opportunity. And it's all possible because of being loved.

I started my fourth year of residency in July. My father has finally come around and is now convinced I'm somehow going to "change the world of medicine"; that's an ongoing conversation. He plays for me whenever I visit home, and sometimes I sing along. My mother loves to hear about my cases. And my wife walks with me through difficult moments with grace and the kind of love I never expected. As I plan the next steps of my career, I carry them all with me; they live in my body. They're in my hands whenever I care for a patient, comfort a grieving family member, or lift a scalpel – that first, hushed moment before the curtain rises. I am held, and I hold others, a series of bodies moving together and apart, making our own kind of music. ■

Biographical Note

Sarah Klapman is a fourth-year General Surgery resident at Queen's University in Kingston, Ontario, Canada. Prior to entering medical school at McMaster University, she completed degrees in both classical music and psychology at Mount Allison University. She then combined these interests in a Master's degree in music neuroscience at Western University. Sarah is currently studying narrative medicine, a field applying literature, philosophy, and advocacy to healthcare. She is excited to apply her unusual skills and background in her future work as a surgical oncologist (a surgeon providing cancer care). She thanks the IJWPC for providing this opportunity to share her story.

BETWEEN RECOGNITION AND NEGLECT

Mohamed Farris Masthan M.

Sree Balaji Medical College, Chennai, Tamil Nadu, India

farrismasthan007@gmail.com

KEYWORDS: Continuity of care; Embodiment in medicine; Health inequity; Healthcare systems; Marginalised communities; Whole person care

She sat so still in the crowded Digital *Seva Kendra*, her infant pressed close against her chest, as if the baby might somehow shield her from the noise and indifference swirling around. People rushed past in every direction, forms shuffled under impatient hands, numbers barked out, instructions repeated like a tired script. She hardly shifted. Her face carried no obvious urgency, just a kind of heavy calm that made me pause. I kept wondering whether she truly grasped what was slipping away from her, or whether endless visits to places like this had simply taught her body to wait in silence.

She came from the *Narikkuravar* community, a nomadic group listed as a Scheduled Tribe in India. She had come seeking the maternity benefits that the government promised women in her situation. But her Aadhaar enrolment had been suspended for months. Every time she tried, the answer was the same: come back later, try again, call the helpline—1947. The number itself felt like a quiet mockery, borrowed from the year of our independence. The need was plain to see. Her body, still tender from recent childbirth, deserved that support. Yet the system refused to see her without that single piece of official recognition.

Anger rose in my chest as I watched. As a postgraduate student in Community Medicine, I could not simply stand aside. I stepped forward, spoke directly to the officials, and searched for any loophole or alternative route. Their responses stayed flat, cold, and procedural, as if her life and her child's future were just another file to be processed. I could stand beside her that afternoon, offering what little solidarity I had. But I could not force the paperwork to bend. In the end, we walked away with nothing resolved. Her body, carrying both new life and old exhaustion, remained locked outside the help that was supposed to reach it.

Not long after that day, I visited a home and met a 63-year-old patient who had been diagnosed with tuberculosis six years earlier. He had given up treatment after only six months. He still smoked heavily, the cigarette almost permanent between his fingers, and carried a long habit of drinking that seemed to dull whatever edges life threw at him. When I first saw him, he stood outside with his friends, laughing loudly, talking as though sickness belonged to someone else entirely. Inside the small, poorly ventilated house, the air felt thicker. Several family members, including young children, shared that single cramped room. His wife pulled me aside and described, in a low, tired voice, how she scrubbed the bathroom after every use, trying desperately to keep infection away from the little ones. There was simply no space to isolate him. The daily work of protecting the family had quietly fallen on her shoulders, and on the household as a whole.

He admitted without hesitation that he had tuberculosis. Yet he did not seem to connect his smoking, his movements, his very presence in that crowded room to the danger drifting toward his wife and children. Care for him came only when the cough grew fierce enough to drive him to a nearby clinic. Otherwise, treatment was simply abandoned. He had even torn up his old medical records and the tuberculosis card in some moment of frustration or denial, erasing much of the trail that might have helped. When I examined him, his thin frame told its own story—clear marks of chronic illness written across his body. I spoke to him carefully about the risks of leaving it untreated, about drug resistance, and about the free support available through public programmes. He nodded slowly, took my phone number, and promised he would come. No one ever did.

That visit sat heavily in my chest for days afterward. Care had begun once, years ago, but it had not held. Addiction, gaps in understanding, and the complete absence of steady follow-up had broken everything apart. The illness remained right there in the house. The family learned to live around it, cleaning and breathing the same air with quiet fear. His body carried the disease openly for all to see, while any real care around it quietly slipped away.

Then there was the woman in the marginalised settlement, also from a tribal background. For more than two years, she and her family had moved between private clinics, chasing treatment for infertility caused by polycystic ovarian syndrome. Tests kept piling up, and so did the expenses, until the money simply ran dry. Eventually, the visits stopped. Cost was part of it, of course, but deeper confusion and the lack of any clear direction played their role too. She understood so little about what was happening inside her own body, and no steady path forward ever appeared. Her husband stayed mostly distant from the struggle, lost in his own routines of smoking and drinking. The entire weight of continuing treatment fell on her alone. Government facilities existed not far away, yet they never became the consistent support her life actually needed. Without guidance or someone to help her keep going, her efforts slowly weakened and faded. The body that carried both the illness and the deep longing for a child received care only in broken pieces, then less and less, until it felt almost abandoned.

These three encounters refused to leave my mind during those months of field work. Each one revealed, in its own painful way, how a person's body becomes caught between the pressures of family, the harsh realities of living conditions, and the rigid rules of healthcare systems. In the first, a single piece of paper decided whether a mother could receive the basic support her body needed after giving birth. In the second, a man's stubborn habits kept spreading risk while his family silently bore the daily burden of fear and adjustment. In the third, a woman carried the physical pain and emotional ache of infertility almost entirely on her own, watching care begin and then slowly dissolve.

As a trainee in community medicine, these moments created a sharp, uncomfortable tension inside me. Our training speaks loudly about equity, about reaching the unreached, about making a real difference in people's lives. Yet in practice, my hands often felt small and limited. I could sit and listen, explain the risks as clearly as I knew how, offer whatever advice lay within my power, and walk alongside someone for a single visit. But I could not tear down the walls of documentation, I could not keep motivation alive across long, difficult months, and I could not reshape the way families divided their emotional and practical loads. That limitation pressed on me every time I left a home or an office, knowing the body I had just seen would continue carrying burdens the system only partly understood or addressed.

Power moves in such quiet, stubborn ways through these encounters. Administrative rules that claim to welcome everyone somehow end up pushing certain bodies to the side. Treatment programmes expect patients to return again and again, yet the daily struggle for survival in crowded homes or uncertain incomes pulls people in completely different directions. Families step in to carry what formal care leaves behind—adjusting, cleaning, worrying, sometimes growing exhausted and resentful in the process. The body becomes the exact place where all these forces collide: shaped by distant policies, pressed by immediate environments, and held within relationships that both sustain and constrain.

Across these three stories, one truth felt painfully clear. Care does not simply flow from need alone. It depends on whether the person is truly seen and recognised by the institutions that hold the keys to help, whether that engagement lasts beyond the first hopeful contact, and whether genuine support exists that actually fits the messy realities of their daily life. When any one of those pieces weakens or fails, care turns uncertain, incomplete, sometimes almost illusory.

These experiences have quietly changed how I think about embodiment in medicine. The body is never only the site of disease. It lives entangled inside relationships, inside harsh environments, inside systems that quietly decide what kind of care can actually reach it. To care properly, we must learn to pay attention to these surrounding conditions with the same careful seriousness we give to symptoms, to medicines, to test results. In the daily grind of community medicine and public health work in India, that attention often begins with nothing more dramatic than simply noticing what the system chooses to make invisible, and

what ordinary families carry, day after quiet day, without complaint or fanfare. The real challenge lies in keeping that noticing alive, even when one doctor's actions can reach only so far. ■

Biographical Note

Dr. Mohamed Farris Masthan M. is an MD postgraduate in Community Medicine at Sree Balaji Medical College, Chennai, with a background in medicine, public health, and community research. His interests include healthcare delivery, health equity, epidemiology, and medical education. Through postgraduate training, Dr. Mohamed Farris Masthan M. worked with underserved communities, shaping his understanding of illness beyond clinical aspects. His research focuses on disadvantaged populations, including adverse pregnancy outcomes and substance use. Dr. Mohamed Farris Masthan M. is also interested in strengthening primary healthcare via digital health, AI, and evidence-based practice. He aims to work at the intersection of clinical medicine, public health, and health systems to make care more accessible and responsive.

STORYLINES

FROM HOLLOWNESS TO HOPE

Sandra Derghazarian

Montreal Neurologic Clinic, Montreal, Quebec, Canada

sandra.derghazarian@gmail.com

KEYWORDS: Hope; Growth; Wholeness; Balance

It's a cool spring morning and I am going for a run. The snow is gone and there is mud galore, but not yet enough warmth for the buds to reveal themselves. Nevertheless, the city workers have started going around in their pickups doing their landscaping work. As I pass through the park, I see a large tree they felled right next to the path. It is a sad sight; my running slows down. The tree lays on the ground, amputated - no trace left of its majestic height and beauty. No connection to its underground anchor of support. The poignancy of its downfall is amplified by a message spraypainted on its very large base: "My inside is hollow".

The message echoes in my mind as I pick up my pace. "Is *my* inside hollow?" I wonder. I check in with myself: no, I do not feel hollow. And yet, something does. These *times* feel hollow. We are collectively mesmerized by the light of our screens and their shimmering promises for more. As we turn our faces to this artificial light, our anchor to reality – attention to what is within us, in front of us and around us – is mercilessly relegated to oblivion. Our own unique, individual truth is abandoned, and the unique truth of the real world remains unexplored and untested. We forget about the other sources of light – relationships, community, nature and the inner world.

My thoughts are interrupted when I notice another runner. I raise my hand and say hello as we pass each other. He looks up with a smile. But in that exact moment, the cellphone in his hand rings. He looks torn for a split second until he turns to the screen to answer the call.

My mind goes back to the spraypainted message. And then to medicine. Is medicine hollow? No, I decide, medicine is not hollow. However, it is unbalanced. Some parts – like the biomedical sciences - are booming. This knowledge is like a lush and rapidly growing forest from which we derive most of our medical fruits. And other parts – like the knowing of ourselves and the knowing of our patients – is an arid landscape. In the current context of scarcity of time and resources, the promise that more data will bring more certainty is very attractive. However, it runs the risk of hollowing out the soul of our practice. The search for certainty reduces the patient to data and disconnects them from the meaningful story of their body and personhood. The search for certainty also reduces us, practitioners, to our analytical minds and severs us from our natural desire to relate to each other with respect and humanity. Both patient and practitioner lose the recognition of themselves as a whole person.

I arrive at the halfway mark of my run and turn around. There, across the street, I see the same runner as before. He waves at me and, pointing to his phone, says “Hello! I’m sorry!” I wave back with a big smile. The interaction leaves me feeling joyful and hopeful.

As I head home, I recall an African proverb: “A falling tree will make more noise than a growing forest.” There must be a borderland, I think, a place in the desert where new trees are silently growing. A place in the medical ecosystem in which there is a greater balance between the lush and the arid. A place in our society where individuals are anchoring themselves in reality and in their own truth. Come to think of it, there is. I know individuals who practice medicine with the goal of holding both knowledge *and* knowing in the same space. I think of this journal and its readership who work hard to name and validate that space. I see the younger generation embodying the concept of wholeness, groundedness and respect for humanity. I think of the runner finding joy in a moment of unexpected connection. You and they are the growing trees – the forest slowly expanding into the hollowness. You and they are the new life that is quietly changing the landscape of medicine and our modern society. You and they fill me with bright hope. ■

Biographical Note

Sandra Derghazarian is a community neurologist and a physician coach who has loved stories for as far back as she can remember. *Storylines* is a column in which she shares stories about work and life. As much as possible, she tries to stay loyal to the messy and sometimes contradictory experiences of everyday life.

COUNTERING SOCIAL DEATH: A CONCEPTUAL FRAMEWORK FOR RADICAL, COMMUNITY-SUPPORTED PALLIATIVE CARE IN WHOLE PERSON MEDICINE

Oyeleke Stevens Olaide, Adekunle A. Adebayo, David O. Oladokun, Olufunmilayo Ikotun

Department of Anaesthesia and Critical Care, Lagos State University College of Medicine, Lagos, Nigeria

Corresponding Author

Oyeleke Stevens Olaide, Clinician and Lecturer, Department of Anaesthesia and Critical Care, Lagos State University College of Medicine

oyelekeolaide@gmail.com

KEYWORDS: Whole person care; Palliative care; Social death; Compassionate communities; Mutual aid; Decolonial death studies

Introduction

Modern biomedicine has earned its reputation for technical precision. The same precision, however, has steadily narrowed the clinical gaze to the physical body and its measurable dysfunctions, leaving the biographical, relational, and existential dimensions of illness at the margins of professional attention.[1,2] For those approaching the end of life, in particular, the cost of this narrowing is high. Care that could be woven into family, neighbourhood, and religious community is instead transferred to specialist environments where monitoring equipment, protocols, and shift handovers structure the day. The dying trajectory becomes, in this setting, an episode to be managed rather than a life passage to be accompanied.[3]

Whole person care (WPC) arose precisely to challenge this drift. Anchored in the work of Balfour Mount and elaborated by Tom Hutchinson and colleagues at McGill, WPC does not deny the value of biomedical intervention; it insists that cure and healing are distinct projects, and that the latter remains both possible and necessary when the former is exhausted.[2,3] Healing, in this tradition, is not a synonym for recovery. It names the movement of a person toward coherence, meaning, and wholeness even as the body fails. The clinical encounter, reoriented in this way, becomes a site where a suffering person is met as a subject rather than processed as an object.[3]

Yet WPC has always carried an unresolved tension. Its practice can be isolating. The whole person care movement is maturing, and its leading voices now argue that the field can no longer treat community as a backdrop to clinical work, but must recognise it as a therapeutic vector in its own right. The direction is clear: WPC must turn outward.

The most developed framework for that outward turn is 'public health palliative care' (PHPC), the project Allan Kellehear began advancing in the late 1990s.[4] PHPC begins from a simple inversion: dying is, first, a social event with a medical component, not a medical event with social trimmings. The inversion is not rhetorical. It follows from an observable fact—namely, that people living at home with life-limiting illness spend only a small fraction of their remaining days in direct contact with formal healthcare professionals, and the overwhelming majority of their experience is shaped by neighbours, kin, local institutions, and the physical environment in which they live.[5,6] Kellehear's Compassionate Cities programme translates this observation into civic practice, asking municipalities to treat end-of-life care as a public health responsibility comparable to sanitation or road safety.[5]

When the civic infrastructure that PHPC presupposes is absent, fractured, or bypassed by clinical systems that concentrate care inside institutions, a specific harm follows. Borgstrom names it 'social death': the process by which a person still biologically alive comes to be treated as though they were already gone.[7] These three strands—whole person care's commitment to relational healing, public health palliative care's socio-ecological orientation, and critical thanatology's analysis of social exclusion—converge to open a path toward reimagining end-of-life care. This review synthesises these strands to propose a comprehensive framework for countering social death through radical, community-supported palliative care. The argument unfolds in four movements: a deconstruction of social death's mechanics; an account of phenomenological accompaniment and mindful congruence at the bedside; an engagement with decolonial praxis and mutual aid; and a consideration of how the ninety-five percent of lived experience outside the clinic can be reclaimed through compassionate communities and death doulas. Strategic recommendations for clinical practice, professional education, and health policy follow.

Deconstructing Social Death: Sociological and Psychological Mechanics

The concept's empirical foundation is Sudnow's 1967 ethnography of dying in American hospitals, *Passing On*, which documented how ward staff rationed attention according to a tacit calculus of social viability, conversed about patients in their presence as if absent, and occasionally initiated autopsy paperwork before biological death had occurred.[8] Sudnow's central finding was structural rather than incidental: in institutional settings, social death is not an aberration but a routine by-product of how acute care organises its work. The patient's personhood is gradually bracketed; the body becomes the sole object of custodial management. Froggatt's later study of English nursing homes extended this analysis to long-term settings, showing how the sequestration of residents from the outside social world produces a slow, institutional form of social dying that precedes biological death by months or years.[9]

Sweeting and Gilhooly sharpened the analytical picture by mapping which populations are most exposed to premature social termination. Their review identified three groups at extreme risk in late-modern societies: the very old, those in the advanced stages of terminal physical illness, and those whose cognitive decline—through dementia or persistent vegetative states—strips them of the capacities on which modern cultures predicate full personhood.[10] In a complementary empirical study they showed how dementia, in particular, accelerates social death: relatives and carers begin to withdraw emotionally before biological death, and the person living with dementia is progressively excised from the relational register of the living.[11] The mechanism, they argued, is cultural rather than individual. High modernity rewards future-oriented productivity, cognitive rationality, and autonomous self-governance; those who visibly fail on these dimensions are reclassified out of full social membership.

Broader scholarship extends this analysis by identifying additional vectors of exclusion. People living with highly stigmatised conditions experience a premature withdrawal of relational contact long before the active dying phase begins.[12] Further, neurodivergent individuals confront distinctive systemic barriers to social connection within conventional clinical environments that compound the risk of relational abandonment when physical vulnerability is superimposed on cognitive difference.[13] These findings confirm that social death is not a uniform endpoint but a differentially distributed risk, shaped by stigma, neurotype, and the politics of recognition.

At the micro-relational scale, two converging bodies of work explain how social death is enacted in everyday encounters. Kitwood's formulation of "Malignant Social Psychology," developed in the context of dementia care, challenged the assumption that the cognitive and functional decline observed in institutionalised residents is driven by neuropathology alone. Kitwood argued that a substantial portion of that decline is produced by depersonalising social environments—by the infantilisation, objectification, ignoring, banishment, and invalidation that residents routinely experience at the hands of well-meaning but undertrained carers.[14] Sabat extended this analysis through the companion concept of 'Malignant Positioning'. When caregivers position a person as "as good as dead" or cognitively empty, Sabat showed, they strip that person of the social personae through which agency

is exercised, and the positioning becomes self-fulfilling: the predicted decline is produced by the very interaction that predicted it.[15,16] Social death, on this account, is not something that merely happens to a person; it is something that is done to them, interaction by interaction, by the social world around them.[7]

Phenomenological Accompaniment and Mindful Congruence

If social death is enacted interaction by interaction, then the counter-practice must also be enacted interaction by interaction. Whole person care provides the conceptual frame for this counter-practice by re-distinguishing cure from healing. Cure targets the disease; healing targets the person, restoring a sense of coherence and meaning even when biological recovery is out of reach.[2,3] The clinical question becomes not only “what can be done for this body?” but also “how can this person be accompanied?” The latter question, once asked, redirects professional attention from intervention to presence.

Arman and Rehnsfeldt's phenomenological study of suffering and nursing care gives empirical substance to that redirection. They describe what patients call “the little extra”—not a separate procedure but a quality of attending that transforms the experience of care. Presence, on their account, is a three-dimensional practice: being present to the patient, being present to oneself, and being anchored in the present moment, with the act of presence itself received as a kind of gift.[17] This is not a soft adjunct to “real” medicine. It is the medium through which suffering becomes endurable and through which the threatened dissolution of personhood is held at bay.

Hutchinson's model of mindful clinical congruence operationalises this phenomenological insight for everyday practice.[2] Drawing on the ‘family-systems communication’ theory of Virginia Satir, Hutchinson asks the clinician to remain simultaneously aware of three intersecting dimensions of every encounter: the Self (the clinician's own interior life, vulnerabilities, and unfinished grieving), the Other (the patient as a biographical subject, not a diagnostic instance), and the Context (the institutional pressures, time constraints, and bureaucratic demands that shape what is clinically possible).[2,18] Congruence, in this framework, is the disciplined maintenance of awareness across all three dimensions at once. When the discipline lapses, the clinician tends to default to one of Satir's defensive survival stances—the super-reasonable retreat into pure technical rationality, the placating deflection of emotional demand, or the blaming projection of interior discomfort onto the patient.[18] These defaults are not character flaws. They are predictable responses to the emotional load of clinical work, and they are also the micro-mechanism through which social death is reproduced at the bedside: the patient is positioned, interaction by interaction, as an object to be managed rather than a person to be met.

Decolonizing Death Work: Decolonial Praxis and the Ethics of Mutual Aid

Bedside presence, however congruent, cannot by itself dismantle the structural conditions under which social death flourishes. A second line of critique is needed, one that interrogates the socioeconomic and historical architectures in which dying occurs. The decolonial strand of death studies has been particularly forceful here, demonstrating that what counts as a “good death” has always been culturally and historically contingent.[6]

Powell and colleagues' account of palliative care development in Africa makes the structural point concrete. Across many African settings, they show, the professionalised hospice model imported from high-income contexts collides with realities of extreme resource constraint, geographic dispersion, fragile health-system infrastructure, and linguistic-cultural plurality. Where the model is imposed without adaptation, it either fails to reach the majority of those who need it or actively displaces indigenous and community-led deathways that had previously sustained the dying and the bereaved.[20] The lesson is not that professional palliative care is unwelcome in low-resource settings; the lesson is that its introduction must be negotiated with the communities it purports to serve, not delivered to them as a finished product.

Rotolo and colleagues' description of the Peer Medical Foundation demonstrates how this works in practice: their grassroots, peer-led model redistributes both material resources and relational recognition to populations whom professionalised services have historically failed to reach,[22] showing that mutual aid is not merely a supplement to professional care but a core mechanism of whole person care for structurally marginalised communities.

Reclaiming the Ninety-Five Percent: Socio-Ecological Palliative Dynamics

The integration of bedside congruence with decolonial mutual aid requires a structural reorientation of how society allocates responsibility for dying. For several decades the professionalisation of palliative medicine has encouraged a quiet civic delegation: death has been handed over to specialist clinicians, and community confidence in accompanying the dying—what Kellehear calls death literacy—has eroded in parallel.[5,6] Reclaiming the overwhelming majority of the dying experience that takes place outside formal clinical contact requires the deliberate cultivation of community assets and the rebuilding of local confidence. The Compassionate Communities and Compassionate Cities movements, which Kellehear built on the Ottawa Charter for health promotion, translate this reclaiming into civic practice: municipalities are invited to treat end-of-life care as a public health responsibility, designing schools,

workplaces, faith institutions, and public spaces that explicitly recognise and support dying, caregiving, and bereavement.[5]

A growing workforce of non-clinical end-of-life companions has emerged to occupy the relational space that Compassionate Communities names. Death doulas, sometimes called end-of-life doulas, work as non-clinical care partners who provide continuous emotional, practical, and spiritual accompaniment across the dying trajectory and into early bereavement. Yoong and colleagues' scoping review of the death doula role synthesised the international literature and identified doula functions ranging from advance care planning conversations and non-pharmacological symptom support to vigil presence in the final days and post-mortem ritual facilitation.[23] Because doulas are not constrained by shift rotas or institutional protocols, they can offer a continuity of presence that is structurally unavailable to clinical staff, and in doing so they bridge the ninety-five percent of lived experience that formal services cannot reach. This observation, foregrounded by Kellehear, reflects the evidence that individuals with life-limiting illness spend only a small fraction of their remaining time in direct contact with formal healthcare professionals, while the overwhelming majority of their experience is shaped by family, neighbours, and community.[5,6] Stein's earlier analysis of mutual aid in bereavement groups complements this picture: when the bereaved support the newly bereaved, the therapeutic benefit flows in both directions, and the isolation that often follows loss is structurally interrupted.[24]

The doula workforce, however, remains unregulated and unaccredited in most jurisdictions, and the resulting ambiguities are not trivial. Role boundaries with clinical teams are often unclear, ethical oversight is inconsistent, and the fee-for-service model that predominates in many settings threatens to reproduce, rather than disrupt, the socioeconomic exclusions that the decolonial critique identifies. Collins and colleagues' practice-oriented review of what palliative care clinicians should know about end-of-life doulas offers a constructive path forward: clinical services should move from professional territorialism toward collaborative integration, treating doulas as essential partners in the holistic care team while working to establish the ethical and structural safeguards the role requires.[25]

Synthesis and Strategic Recommendations for Whole Person Care

The threads of the argument can now be drawn together. To counter social death and reclaim the ninety-five percent of lived experience at the end of life, whole person medicine must integrate three interdependent layers: the relational depth of mindful clinical congruence at the bedside; the socio-ecological orientation of compassionate communities in civic life; and the structural solidarity of mutual aid networks that centre those whom professionalised services have historically failed. The evidence reviewed demonstrates that social death is not an inevitable consequence of biological mortality. It is an active, socially constructed process of exclusion that can be dismantled through intentional clinical, educational, and community interventions. Four strategic recommendations follow.

First, healthcare systems should transition from a centralised, professionalised service-delivery model toward an asset-based community development approach.[5] Palliative care organisations should actively partner with local mutual aid networks, community centres, and neighbourhood associations, treating them as essential collaborators rather than as referral destinations.[21] The stance the clinician adopts in these partnerships matters as much as the partnership itself: professional services should bring technical medical support while deferring to the community's expertise in relational accompaniment and practical resource redistribution, rather than colonising community spaces with clinical protocols.

Second, clinical intake procedures should be redesigned to systematically map the patient's socio-ecological network.[1] Palliative care assessments that limit themselves to physical symptom scores miss the social determinants of dying that the ninety-five percent rule identifies. Evaluations should therefore identify local community connectors, neighbour support systems, and non-medical advocates such as death doulas, and should integrate these external actors into formal care-planning discussions.[23,25] Aligning clinical interventions with the patient's daily social reality and cultural preferences is the structural precondition for preventing institutional isolation and relational abandonment.

Third, medical and professional healthcare curricula should be restructured to integrate critical thanatology, decolonial death studies, and relational communication training.[2] Future clinicians must learn to recognise the historical and structural inequalities that shape end-of-life trajectories for marginalised and racialised populations, and to decenter Euro-American assumptions about "the good death" that travel as universal when they are in fact particular.[6,20] This critical training should be combined with Hutchinson's model of mindful clinical congruence, equipping students with the psychological disciplines required to remain emotionally available to patients without defaulting to the defensive stances that produce both burnout and social death.[2,18]

Fourth, healthcare administrators should establish structural stewardship programmes that sustain the emotional and moral resources of the clinical team. Recognising that the clinician's self is the primary instrument of healing, organisations must reject individualistic wellness models and implement collective, team-based reflective practice and mutual supervision instead.[19] By sharing the moral weight of complex clinical decisions and validating the emotional labour of care, institutions can cultivate a sustainable clinical culture that prevents professional depletion and ensures the continuous, compassionate accompaniment of the dying person.

Conclusion

The evidence demonstrates that social death is not an inevitable consequence of biological mortality but an active, socially constructed process of exclusion that can be dismantled. Integrated strategies

that transition healthcare systems from professionalised service delivery to asset-based community development, redesign clinical intake to assess socio-ecological networks, restructure medical curricula to incorporate critical thanatology and relational communication training, and establish institutional stewardship programmes that sustain clinicians' emotional resources can move whole person medicine closer to the ground. In doing so, they transform the end-of-life trajectory from an experience of medicalised isolation into a shared, relational practice of collective accompaniment—and, in the best cases, into a profound recognition of the shared humanity that survives even the body's failure.

Declarations

Ethics approval. Not applicable. This article is a narrative review of previously published literature and did not involve human participants, patient records, or identifiable data; institutional ethics committee approval was therefore not required.

Funding. The authors received no external funding for this research. The work was conducted as part of the authors' academic responsibilities at the Lagos State University College of Medicine.

Conflict of interest. The authors declare that they have no competing financial interests, personal relationships, or institutional affiliations that could be perceived to influence the work reported in this manuscript.

Author contributions. OSO: conceptualisation, literature search, analysis, writing of the original draft, review and editing. AA: critical review and editing of the manuscript. IO: critical review and editing of the manuscript. OD: critical review and editing of the manuscript. All authors approved the final version and accept accountability for all aspects of the work.

Use of artificial intelligence. During the preparation of this manuscript the authors used a large language model (Meta AI) as an assistive tool for three purposes: language editing to improve clarity, grammar, and adherence to journal style; reference verification and structural review for compliance with the International Journal of Whole Person Care manuscript preparation requirements. All AI-generated suggestions were reviewed and edited by the authors, who take full and sole responsibility for the accuracy, integrity, and originality of the final manuscript, including all scientific claims, interpretations, and cited sources. No new empirical data, results, or citations were generated by the AI tool without explicit author verification. The authors further confirm that every reference cited in this manuscript was verified against a published primary source (journal website, publisher record, or PubMed entry) before submission.

Data availability. Not applicable. This is a narrative review of published literature; no original datasets were generated or analysed.

References

1. Watson M, Lucas C, Hoy A, Back L, editors. Oxford Handbook of Palliative Care. 3rd ed. Oxford: Oxford University Press; 2019.
2. Hutchinson TA, editor. Whole Person Care: Transforming Healthcare. Cham: Springer; 2017.
3. Mount BM. Whole person care: beyond psychosocial and physical needs. *Am J Hosp Palliat Care*. 1993;10(1):28–37.
4. Kellehear A. Health-promoting palliative care: developing a social model for palliative care. *Palliat Med*. 1999;13(4):275–79.
5. Kellehear A. Compassionate Cities: Public Health and End-of-Life Care. London: Routledge; 2005.
6. Kellehear A. A Social History of Dying. Cambridge: Cambridge University Press; 2007.
7. Borgstrom E. Social death. *QJM*. 2017;110(1):5–7.
8. Sudnow D. Passing On: The Social Organization of Dying. Englewood Cliffs (NJ): Prentice-Hall; 1967.
9. Froggatt K. Life and death in English nursing homes: sequestration or transition? *Ageing Soc*. 2001;21(3):319–32.
10. Sweeting HN, Gilhooly MLM. Doctor, am I dead? A review of social death in modern societies. *Omega (Westport)*. 1992;24(4):251–69.
11. Sweeting H, Gilhooly M. Dementia and the phenomenon of social death. *Sociol Health Illn*. 1997;19(1):93–117.
12. Alemayehu SK. Building community in the shadows of stigma. *Int J Whole Person Care*. 2026;13(1).
13. Simms K. A place on the spectrum. *Int J Whole Person Care*. 2026;13(1).
14. Kitwood T. Dementia Reconsidered: The Person Comes First. Buckingham: Open University Press; 1997.
15. Sabat SR. Malignant positioning and the predicament of people with Alzheimer's disease. In: Hughes JC, Louw SJ, Sabat SR, editors. Dementia: Mind, Meaning, and the Person. Oxford: Oxford University Press; 2006. p. 85–98.
16. Sabat SR. The Experience of Alzheimer's Disease: Life Through a Tangled Veil. Oxford: Blackwell; 2001.
17. Arman M, Rehnsfeldt A. The 'little extra' that alleviates suffering. *Nurs Ethics*. 2006;13(2):116–27.
18. Satir V, Banmen J, Gerber J, Gomori M. The Satir Model: Family Therapy and Beyond. Palo Alto (CA): Science and Behavior Books; 1991.
19. Shanafelt TD, Hasan O, Dyrbye LN, Sinsky C, Satele D, Sloan J, et al. Changes in burnout and satisfaction with work-life balance in physicians and the general US working population between 2011 and 2014. *Mayo Clin Proc*. 2015;90(12):1600–13.

20. Powell RA, Mwangi-Powell FN, Kiyange F, Radbruch L, Harding R. Palliative care development in Africa. In: Silbermann M, editor. *Palliative Care for Chronic Cancer Patients in the Community*. Cham: Springer; 2015. p. 93–110.
21. Franco-Klothes VY, Topen M, et al. Mutual aid as decolonial praxis: a reflection on practice and a call to action. *J Glob Indigeneity*. 2021 [cited 2026 Jun 15]. Available from: <https://www.journalofglobalindigeneity.com/article/151828-mutual-aid-as-decolonial-praxis-a-reflection-on-practice-and-a-call-to-action>
22. Rotolo S, Selvanayagam S, Peer LS. Community as care: solidarity, whole person care, and lessons from the Peer Medical Foundation. *Int J Whole Person Care*. 2026;13(1).
23. Yoong SQ, Goh HS, Zhang H. Death doulas as supportive companions in end-of-life care: a scoping review. *Palliat Med*. 2022;36(5):795–809.
24. Stein J. Group work with bereaved individuals: the power of mutual aid. *Omega (Westport)*. 2004;48(3):237–49.
25. Collins ES, et al. Top ten tips palliative care clinicians should know about end-of-life doulas. *J Palliat Med*. 2025;28(1).

Biographical Note

Oyeleke Stevens Olaide is a clinician and academic in the Department of Anaesthesia and Critical Care at Lagos State University College of Medicine, Nigeria. His work bridges intensive care and palliative medicine, with a strong focus on integrating whole-person care frameworks in diverse clinical settings. He is deeply committed to exploring the socio-ecological dimensions of end-of-life care, advocating for community-supported models that counter social death. Through his research and clinical practice, he strives to advance compassionate, equitable, and decolonial approaches to healthcare delivery and dignified dying.