

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.