The Silent Revolution of Long Covid: Knowledge, Patients, and the Future of Care

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Abstract

Long COVID is an emerging condition characterized by persistent multisystemic symptoms affecting a significant proportion of patients following SARS-CoV-2 infection. Its still partial recognition reveals tensions between scientific knowledge, clinical practices, and lived experiences. This article offers an epistemological analysis of the obstacles encountered in the recognition and management of Long COVID, drawing on concepts such as meta-ignorance, the Dunning-Kruger effect, quaternary prevention, and shared knowledge dynamics. It highlights the educational, political, societal, and gender-related challenges associated with this condition, and advocates for a profound transformation of the healthcare system toward greater integration, reflexivity, and active listening.

Keywords : Long COVID ; epistemology ; primary care ; meta-ignorance ; quaternary prevention ; gender ; patient knowledge

Résume

Le Covid long constitue une pathologie émergente aux manifestations multisystémiques persistantes, affectant une proportion significative de patients après infection par le SARS-CoV-2. Sa reconnaissance, encore partielle, révèle les tensions entre savoir scientifique, pratiques cliniques et expériences vécues. Cet article propose une analyse épistémologique des obstacles rencontrés dans la reconnaissance et la prise en charge du Covid long, en mobilisant des concepts comme la méta-ignorance, l'effet Dunning-Kruger, la prévention quaternaire et les dynamiques de savoirs partagés. Il met en lumière les enjeux éducatifs, politiques, sociétaux et de genre liés à cette pathologie, et plaide pour une transformation profonde du système de santé vers plus d'intégration, de réflexivité et d'écoute.

Mots-clés : Covid long ; épistémologie ; médecine générale ; méta-ignorance ; prévention quaternaire ; genre ; savoirs patients

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[*] Both authors are family physicians.

> *I hate doctors, they never listen to me.*
>
> — M. Jamoulle, Consultation 2023 (a woman)

A Persistent Disease with Systemic Consequences

Long Covid, or post-Covid-19 syndrome, is now recognized as a clinical entity with diverse neurological and mental manifestations. Recent research highlights complex neuroimmunological mechanisms involved in its pathophysiology. Post-mortem studies and animal models suggest that SARS-CoV-2 infection can lead to persistent microglial activation, disruption of the blood-brain barrier, and chronic neuroinflammation. These processes may account for cognitive symptoms, such as memory and attention deficits, as well as the mental manifestations observed in some patients. A deeper understanding of these underlying mechanisms is essential for developing targeted and effective therapeutic approaches for individuals suffering from Long Covid [1].

Long Covid refers to a persistent constellation of multisystem symptoms that arise after an acute SARS-CoV-2 infection, regardless of the initial severity. Affecting around 10 to 20% of those infected, it represents a major public health concern [2]. In the most severe and long-lasting cases, patients are unable to work, feel estranged from themselves, and mourn the loss of who they used to be. Teenagers have been robbed of their adolescence and forced to abandon their schooling. It impacts millions of patients worldwide, compromising their quality of life, reducing their ability to work, and generating considerable economic, social, and political costs. However, its institutional recognition remains uneven, and both medical and political responses struggle to take shape [3, 4].

> *In April, I went back to my doctor because I was really, really exhausted, and that's when he took me off work again.*
> *So, was the diagnosis Long Covid or not ?*
> *No, at that point — just like at the beginning — they hadn't really identified it as Long Covid. The doctor listed it as depressive symptoms...*
> *And for the extension, he kept the same thing, afraid the insurance might send me back to work. Ah no, he wrote down anxiety–depressive symptoms.*
>
> — M. Jamoulle, consultations, 2025

A Divide Between Science and Medical Practice

In this context, the attitude of the medical community towards Long COVID raises profound questions and calls for genuine epistemological reflection. While numerous scientists from fields such as HIV research or immunology have redirected their efforts toward understanding SARS-CoV-2 and its long-term consequences, some segments of the medical profession have been slower to acknowledge the evolving scientific evidence. This hesitancy has, at times, contributed to insufficient clinical recognition of the condition [5]. As a result, many patients report feeling abandoned, often navigating a fragmented healthcare system where they are referred from one specialist to another without a coherent diagnostic or therapeutic framework [6].

A gap is widening between patients and caregivers, but also between clinicians and researchers. Never before has a pathology generated so many publications in such a short time, yet the majority of healthcare professionals — both general practitioners and specialists — remain in a state of ignorance that sometimes verges on obscurantism. Some adopt attitudes of defiance [7] towards scientific data, a mistrust that paradoxically fuels defensive medicine rather than a medicine based on trust and dialogue. This defensive medicine [8], born of risk aversion and a climate of mutual suspicion, further weakens the therapeutic alliance and drives clinical practice away from research — to the patient's detriment.

> Testimony of a 38-year-old patient, language teacher ;
> *When I crash, the symptoms are almost always the same : crushing fatigue, a burning sensation in my brain, the feeling of molten lead running through my veins, pain in my hands and feet, memory and speech problems, difficulty walking, occasional hair loss, chest pain near the heart, and, since September, trouble breathing. But there are times when I feel absolutely fine, and I make the most of them. Overall, things are improving—slowly but surely. I was first infected in October 2020*
>
> — M. Jamoulle, Consultation, 2024

Toward a Silent Biological Revolution

Several factors may help explain this situation. Scientifically, we are witnessing a true qualitative leap. Biologically, the rise of transcriptomics, proteomics, systems immunology, and neurobiology is reshaping traditional frameworks for understanding disease [9]. In this context, managing Long Covid requires rethinking diagnostic paradigms : it involves rehabilitating imaging tools once considered outdated, such as SPECT-CT brain scans [10]—which, in some cases, are the only ones to reveal perfusion anomalies—while also calling on cutting-edge technologies such as functional magnetic resonance spectroscopy (fMRS) [11], magnetic resonance spectrometry (MRS) [12], or fluorodeoxyglucose positron emission tomography (18F-FDG PET scans) [13], which can detect metabolic, neuroinflammatory, or energetic alterations invisible to conventional tests. However, the speed with which these advances are unfolding in basic research contrasts sharply with their still-limited adoption in routine clinical practice.

Fragmented Care in a Hyper-specialized System

In terms of care organization, the dominant biomedical model has historically evolved based on increasing specialization. While this has led to major advances in understanding pathophysiological mechanisms and targeted treatments, it has also contributed to fragmented care. Patients are no longer approached as whole persons, but as a sum of biological systems, each governed by a different domain of expertise [14]. This organ-specific, compartmentalized approach—typical of hospital medicine—is ill-suited to complex, multisystemic, and evolving conditions such as Long Covid.

This fragmentation is compounded by growing medical technicity, where clinical relationships are often relegated to the background in favor of paraclinical tests, and by the commodification of healthcare systems, where economic, profitability, and productivity logics often guide care pathways [15]. One might fear that, behind a professed ethics of care, the patient is ultimately treated as an exploitable resource. The result is a form of medical wandering, where patients move from one specialist to another, with no one assuming responsibility for the overall clinical picture or for coordinating their care [16].

Moreover, medical information — which should constitute a common good serving both practitioners and citizens — is largely filtered, directed, or even controlled by the pharmaceutical and medical device industries. This phenomenon highlights structural biases that influence the production and dissemination of health knowledge [17]. Conflicts of interest, ghostwriting, and the selective promotion of favorable data all contribute to a distorted view of clinical reality, sometimes fostering institutionalized ignorance. In the case of Long Covid, the lack of immediate therapeutic profitability may have dampened industrial interest, thereby limiting the visibility of the condition within medical spheres.

> *Several times, I feel as though my house is on fire. It's like there's a fog in front of my eyes — it comes on suddenly, and after that... I just can't go on. After reading one page of a novel, or maybe two if I'm lucky, I've already forgotten : who are Mr. and Mrs. ? Who's doing what ? I don't know what I enjoy anymore. Reading a novel — I can't do it. After fifteen or twenty minutes, I get lost. Picking up a TV series ? It's pointless.* — M. Jamoulle, consultations, 2025

Against Fragmentation : A Comprehensive and Protective General Practice

In response to these impasses, many healthcare professionals are calling for a shift toward a more holistic, comprehensive, and relational model of medicine—one that is person-centered rather than organ-focused. This shift involves the revaluation of primary care, where general practice and family medicine play a vital role. Thanks to their proximity, community integration, and deep knowledge of patients' histories, general practitioners are uniquely positioned to provide cross-disciplinary coordination, manage fragmented medical information, ensure continuity of care, and contextualize symptoms within the person's life trajectory [18].

As stated in the WONCA Europe Declaration :

> *General practice [...] is person-centered, community-oriented, and deals with health problems at an early and undifferentiated stage. It provides continuous, coordinated, integrated, and comprehensive care [19].*

This pivotal role is all the more crucial in the face of diffuse and evolving conditions such as Long Covid, which require active listening, a posture of assumed uncertainty, and the ability to navigate across medical specialties without losing the thread of clinical meaning. The general practitioner thus becomes a translator [20], in the sense described by Umberto Eco in Mouse or Rat ? [21], where translation is always an inevitable negotiation between precision and loss of meaning — between specialized knowledge and patients' lived experiences, between scientific uncertainty and concrete needs.

This approach aligns fully with the logic of quaternary prevention [22], which from its inception has positioned itself at the intersection of the medical discourse — focused on identifying diseases — and the patient's discourse — expressing their illness. It embodies a critical stance toward overmedicalization, an ethical vigilance against the risks of iatrogenesis, and a constant attention to the principle of non-maleficence — not causing harm, even with the best of intentions. In the context of Long Covid, quaternary prevention calls for resisting the reduction of complexity into default categorical psychiatric diagnoses, for refusing to disqualify the patient's lived experience and suffering, and for supporting individuals throughout their journey of medical wandering and search for recognition. It restores to medicine its fundamental protective role — the principle of beneficence — that of caring, amid uncertainty, with prudence, attentive listening, and humility [23].

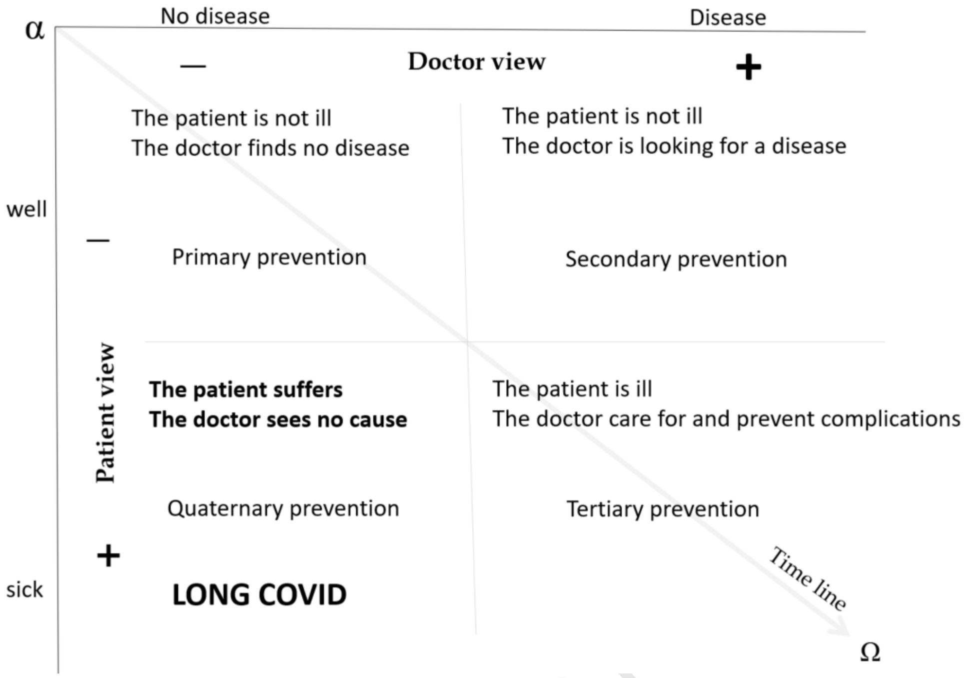

FIGURE 1 – Model of prevention intersecting the patient's lived experience and the physician's actions. In this model, the oblique timeline leads both patient and physician to the Omega point — a reminder of their shared mortality. In Long Covid, the patient becomes lost in quadrant 4 : they feel ill, but the physician does not recognize their condition. To spare the patient this ordeal, the physician must engage in a process of self-monitoring of their own knowledge (Jamoulle, 1986)[24].

A Rigid Medical Education in Need of Reform

The training of healthcare professionals—particularly physicians—remains largely rooted in a transmissive model focused on the accumulation of factual knowledge and the repetition of standardized protocols. This model, inherited from a positivist and hospital-centered tradition, tends to favor memorization and conformity at the expense of critical thinking, clinical uncertainty, and contextual analysis. Students are rarely encouraged to question the construction of medical knowledge, to explore diagnostic gray zones, or to engage with interdisciplinary approaches.

This culture of reproduction—sometimes reinforced by rigid assessment mechanisms—limits the ability of future physicians to manage complex, emerging, or poorly understood situations such as long COVID. It also hinders the recognition of experiential knowledge, especially that held by patients. In this context, medical education inadvertently contributes to the marginalization of so-called "invisible" or "non-objectifiable" conditions.

To overcome these limitations, many voices advocate for deep pedagogical reform. One of the most explored pathways is the introduction of Problem-Based Learning (PBL), developed at McMaster University in Canada in the 1970s [25]. This method places students in active, collaborative clinical problem-solving scenarios, without prior lectures. It encourages critical thinking, interdisciplinary collaboration, and the dynamic integration of foundational knowledge into clinical practice [26].

Recent studies have shown that PBL-based curricula not only improve knowledge retention but also foster a more reflective attitude and openness to complexity [27]. When dealing with multifaceted and ambiguous conditions like long COVID, such competencies are essential.

Rethinking medical education thus means more than modernizing content ; it involves transforming the cognitive posture of future healthcare providers from the outset—shifting from a vertical model of expertise to a stance of scientific humility, active listening, and shared knowledge construction.

Medical education, still largely grounded in the Flexnerian model [28], must be rethought. The cognitive stance should focus more on attentive listening, by emphasizing the caregiver–patient relationship and introducing qualitative, inductive methodologies through early immersive modules in medical training [29]. Anthropology must also be given its place, remembering that the practicing physician is, in their own way, an anthropologist — one who must first immerse themselves in the world of the patient through attentive listening and a particular style of questioning [30], rather than hastily fitting the individual into pre-established diagnostic categories.

> *Sometimes I have trouble... trouble thinking about something, or reflecting on someone... I can't find solutions the way I used to — I used to be much quicker at that. And another thing I struggle with is forgetting things. I forget, and I think : wait, how come ? What did I come here for ? I don't know anymore... That happens to me. Sometimes my son tells me something, and later, I can't remember what he said. Oh right, he told me that... but what else ? I used to have a good memory.* — M. Jamoulle, consultations, 2025

Patients in a Position of Epistemic Inferiority and the Emergence of a Collective Voice

* Patients have traditionally held a symbolically inferior position within the care relationship : their words are often perceived as emotional, subjective, or lacking credibility when compared to medical knowledge legitimized by science. Reluctant to challenge medical authority—particularly in vulnerable contexts—they become susceptible to misleading narratives, sometimes conveyed, knowingly or unknowingly, by healthcare professionals themselves [5]. This epistemic imbalance is further heightened in the case of Long Covid, where the absence of clear biological biomarkers and the normality of test results accentuate the disqualification of patients' accounts.

However, this asymmetry of knowledge has been powerfully challenged by patients' emergence within both public and scientific spaces. It was, in fact, from the patient community—not from the medical world—that the term Long Covid originated, as early as May 2020, on social media [31]. In the face of institutional inaction, patients across the globe—many from academic, healthcare, or activist backgrounds—organized themselves into collectives, conducted surveys, built databases, authored guides, and even published in peer-reviewed scientific journals. This unprecedented reversal of traditional roles has made Long Covid one of the most striking contemporary examples of patient-led research.

Patient organizations—such as Long Covid Support (UK), Body Politic or Long COVID Foundation (USA), Long Covid Belgium, and ApresJ20 (France)—have played a decisive role in raising awareness of the phenomenon, securing institutional recognition, structuring demands for care, and promoting interdisciplinary research centered on patients. Their work has proven essential not only in defining the diagnostic category, but also in compelling public health authorities to respond.

In this respect, Long Covid illustrates a contemporary dynamic in which patients are no longer merely subjects of care, but *agents of knowledge* and drivers of transformation within the healthcare system.

Between Institutional Mistreatment and Oversimplification

The situation of children and adolescents with Long Covid is particularly alarming [32]. Their symptoms—often invisible to conventional examinations—are minimized or even denied by healthcare providers and educational institutions. Due to the lack of recognition of pediatric Long Covid, these children are suspected of malingering or school avoidance, while their families are accused of being overprotective or reinforcing the illness narrative [33]. This dual disqualification—both medical and educational—exposes some to genuine forms of institutional mistreatment [34, 35], including refusal of accommodations, default psychiatric referrals, and unwarranted reports to social services.

This reflex of clinical disqualification falls within a longstanding tradition of marginalizing “medically unexplained” complaints. It is further intensified by the radical novelty of Long Covid, whose symptoms challenge traditional diagnostic frameworks. In the absence of suitable tools, healthcare professionals too often resort to psychiatric labels by exclusion, at the expense of care centered on active listening.

> *I sleep much more than before. I used to sleep only at night, now I sleep almost all the time. Even after an activity or a game, I often have to go lie down. But sometimes I feel heavy... [..]... It’s like my whole body is flattening me — I don’t know how to explain — all flat... Sometimes, when I climb the stairs, I get really out of breath, like an old locomotive... [..]... I’ve had episodes where I fainted : I fall to the ground, I don’t realize it, everything goes black, like a beehive. When I wake up, I realize I’ve fallen... [..]... I used to be good at school. Now, I get tired quickly. Mom reviews lessons with me : sometimes I say nonsense, like “1+1=3”. Then, the next day, it comes back right.*
>
> — M. Jamoulle, Consultation 2025 (11-year-old child)

The Dunning-Kruger Effect and Meta-Ignorance

This reductive reflex can be interpreted through the lens of the Dunning–Kruger effect [36] : professionals who are highly competent in their own field but lack specific training or interest in the subject tend to overestimate their ability to assess the condition. As a result, they may hastily conclude that no pathology is present, failing to recognize the limits of their own understanding.

To this is added a more insidious form of meta-ignorance : not only do some actors not know, but they are unaware that they do not know [37]. This double layer of ignorance—both unrecognized and unquestioned—makes the recognition of Long Covid particularly challenging. It has recently been described as an aggravating factor in public health policy, especially when it impairs the perception of collective risk [38].

A Medical Practice Still Blind to Gender

* Finally, the gender dimension is crucial. Long Covid predominantly affects women—often young, active, and previously healthy. This female prevalence, well-documented in the scientific literature, highlights a structural bias in contemporary medicine, which remains largely androcentric [39]. Women's complaints—diffuse pain, chronic fatigue, cognitive disturbances, neurovegetative dysregulation—have historically been taken less seriously, frequently attributed to psychological or hormonal causes, or dismissed as supposed emotional hypersensitivity.

In the context of Long Covid, this gender bias manifests through a tendency to minimize symptoms, delay access to specialized examinations, or refer women to psychiatric consultations without thorough somatic exploration. This phenomenon is part of a broader logic of systemic discrediting of female patients, well-known in the context of so-called "invisible" chronic illnesses (fibromyalgia, endometriosis, chronic fatigue syndrome). As Woitowich et al. emphasize, the chronic underinvestment in biomedical research on conditions predominantly affecting women contributes to a persistent inequality in care [40]. Long Covid, unfortunately, falls squarely within this continuum.

Political Inertia in the Face of a Silent Public Health Emergency

To these factors must be added a troubling political inaction in many countries. Although evidence continues to accumulate regarding the prevalence, severity, and chronic nature of Long Covid, institutional responses struggle to take coherent shape. This gap is all the more alarming given the significant economic consequences of the condition : prolonged work absences, professional disintegration, increased disability claims, overburdened health insurance systems, and pressure on primary care services.

As Gandjour points out, the costs associated with Long Covid—both direct and indirect—may exceed those of the acute phase of the disease, due to its long-lasting, multifactorial, and often irreversible nature [41]. It is therefore not merely a medical or epidemiological issue, but a macroeconomic and organizational challenge for health systems.

Yet in most countries, the measures put in place remain embryonic : a lack of administrative recognition of the diagnosis, absence of coordinated care pathways, delayed research funding, and a statistical vacuum concerning actual prevalence. In Belgium, this inertia is exacerbated by significant institutional fragmentation across levels of government (federal, community, regional), which renders health governance inefficient, if not inoperative. This structural complexity fuels a sense of abandonment among patients, as well as growing frustration among healthcare professionals faced with a condition they can neither easily diagnose nor refer within a stable care framework.

The result is systemic disorganization, where the absence of political recognition feeds into medical denial, closing a vicious circle of delay, neglect, and unaddressed suffering.

In Switzerland, guidelines for general practitioners were developed through expert consensus [42] to support medical assessments for disability insurance claims. These guidelines prioritize a detailed description of functional limitations over categorical diagnoses. They apply to functional disorders such as chronic pain or fatigue, conditions to which Long Covid is often assimilated. In the Netherlands, the establishment of expertise centers in each province represents an organizational response aimed at structuring the provision of care [43]. Europe, however, continues to fall short — both in acknowledging the scale of the phenomenon and in coordinating a structured response. The result is systemic disorganization, where the lack of political recognition reinforces medical neglect, thus closing a vicious cycle of denial, delay, and unmet suffering.

A Systemic Revealer and an Opportunity for Transformation

Long Covid acts as a revealer of structural vulnerabilities at every level of the healthcare system—and beyond. It embodies the complexity of a condition situated at the intersection of rapidly evolving biomedical sciences, power relations, gender inequalities, and institutional and political inertia. Its symptomatic polysemy, unpredictable chronicity, and interindividual heterogeneity make it a pathology that escapes the conventional frameworks of evidence-based medicine, standardized diagnosis, and targeted treatment.

But beyond the medical and organizational challenge it presents, Long Covid offers a unique opportunity to critically examine our epistemologies of health. It prompts us to rethink how we train healthcare professionals, how we listen to patients, and how we construct—or neglect—care pathways. It forces us to transcend disciplinary silos and to embrace transversal, interprofessional, and participatory approaches.

Ultimately, it confronts us with a fundamental ethical question : what becomes of medicine when it is destabilized by a disease it does not understand ? Far from being merely a medical object, Long Covid constitutes a total social fact, in the Maussian sense of the term [44] : it engages biology, economics, politics, social norms, and our very relationship to knowledge, vulnerability, and recognition. This global, systemic dimension resonates with other health crises, such as that of HIV, in which the medical field was faced with unprecedented forms of suffering, contestation, and reconfiguration of medical knowledge [45].

What stance should caregivers adopt in their practice ?

Responding to the challenge of Long Covid means rebuilding trust between caregivers and patients, reconstructing a shared language between science and clinical practice, and above all, acknowledging that medicine — to remain alive — must constantly be willing to question itself.

Long Covid confronts us with the same uncertainty as all chronic, multisystem conditions of unknown origin. Faced with this, two paths lie ahead :

1. We may be dealing with a rare disease that has not yet been identified. Patient associations focused on rare diseases often highlight the long diagnostic journeys that are sometimes resolved by the discovery of a specific biomarker. One in 17 people may be affected by a rare disease during their lifetime, meaning that general practitioners are likely to encounter such conditions with some frequency [46]. This perspective should encourage us to persist in our investigations and refrain from prematurely closing diagnostic avenues through psychiatrization. In this context, assigning a psychiatric label would amount to a form of reductionism [47].
2. We may instead be dealing with a complex illness with bio-psycho-social determinants. In such cases, we know how endless investigations can have harmful effects, often bypassing the narrative and subjective dimensions of patient suffering by offering off-target responses. The general practitioner must not relinquish their role as translator [20], enabling the patient to articulate their suffering — even when that process is difficult.

How can one navigate such a dilemma : remaining faithful to the legacy of Balint [48] while staying open to scientific advances ? This posture requires a true balancing act.

Following the teaching of Gaston Bachelard [49], who catalogued the obstacles to scientific knowledge at the turn of the 18th and 19th centuries—showing how images, analogies, and metaphors can obstruct understanding—we are called today to undertake a similar effort of psychoanalysis, in an era where the biomedical model dominates. This model promotes a new metaphor : that of a rational, categorical world, comparable to a computer program, in which standards are elevated to the status of untouchable truths [50], leaving little room for the patient's singular voice. How can one navigate such a dilemma : remaining faithful to the legacy of Balint [48] while staying open to scientific advances ? This posture requires a true balancing act. Following the teaching of Gaston Bachelard [49], who catalogued the obstacles to scientific knowledge at the turn of the 18th and 19th centuries—showing how images, analogies, and metaphors can obstruct understanding—we are called today to undertake a similar effort of psychoanalysis, in an era where the biomedical model dominates. This model promotes a new metaphor : that of a rational, categorical world, comparable to a computer program, in which standards are elevated to the status of untouchable truths [50], leaving little room for the patient's singular voice. We have sought to identify these new obstacles. They can be overcome through a disciplined mindset grounded in the constant testing, correction, and, when necessary, rupture of acquired knowledge — thus defining the ethical posture of the general practitioner when facing uncertainty :

- Intellectual and emotional catharsis compels us to reflect and to become clearly aware of our own defensive medical tendencies [51].
- Reforming our mindset will lead us toward a more inductive stance, attentive to the patient's narrative, becoming anthropologists in our own way [30].
- Rejecting the argument from authority entails embracing the postulate of sincerity [52] : the patient must be believed. Otherwise, we risk practicing a form of military medicine that seeks out malingerers — and that is no longer general practice.
- Bachelard's commentators have noted that one must keep reason in a state of inquietude and continue asking questions. This is also the original position of David Sackett, the founder of evidence-based medicine.
- Since it is impossible to define what is not yet known, we must restore the patient's voice. When rigorously collected and structured, this voice constitutes a biological fact in its own right. Coherently organized, it may become a terminological biomarker [53].

When faced with a patient whose test results show *nothing*, yet who can *no longer live as before*, it is essential to suspend judgment, to listen actively, and to acknowledge that our science does not yet know everything. Failing to recognize Long Covid means adding medical violence to suffering. The physician's role is not only to diagnose what is visible, but to accompany what is invisible.

About the authors

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Disclosure

Generative artificial intelligence (ChatGPT, GPT-4, OpenAI) was used to assist with language editing and translation of the manuscript. AI assistance was limited to improving linguistic clarity and did not influence the scientific content or its interpretation. The author reviewed, revised, and approved all content to ensure scientific accuracy and adherence to current evidence. The author takes full responsibility for the integrity of the final version.

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