

Gembloux. April 12, 2024



https://www.leressort.be

# Ethics, epistemology and Long Covid Belgium 2021-2024



Contact;

Family doctor

Marc Jamoulle. MD, PhD

J.Bosh 1500

## Why Ethique?

Derived from the Greek word "*ethos*" meaning "way of life", ethics is a branch of philosophy concerned with human behavior and, more specifically, with the conduct of individuals in society. Ethics examines the rational justification of our moral judgments, studying what is morally right or wrong, just or unjust. https://www.canada.ca/en/treasury-board-secretariat/services/values-ethics/code/what-is-ethics.html

- Yet the experience of hundreds of Long Covid patients is that they have been ignored, not listened to, not supported, not identified as ill in short, denied and abandoned by their doctors.
- it's reasonable to wonder about the origins of this organized ignorance.

## Why epistemology?

Two parts to the term "epistemology": ἐπιστήμη meaning 'knowledge',and λόγος meaning 'discourse'.

• Knowledge evolves with time and tools, and in the case of Belgium's Long Covid we can only observe a gulf between scientists and doctors.

• Most doctors have read nothing about the Long Covid, no serious scientific information or training exists, doctors and scientists live on different planets.

### A chaotic healthcare landscape in our country

• Between doctors and patients

If hundreds of people present the same kind of symptoms, a doctor cannot deny the word of hundreds of people on the pretext that the technology currently available in medicine cannot verify them. He must question the medicine, not the sufferers.

• Between doctors and scientists

most physicians are unaware of current advances in genomics, transcriptomics, proteomics and coagulation.

• Between the scientists themselves

some scientists call Long covid a Hoax

• Between the doctors themselves

the practice of medicine also shows considerable epistemic differences (e.g. naturopaths)

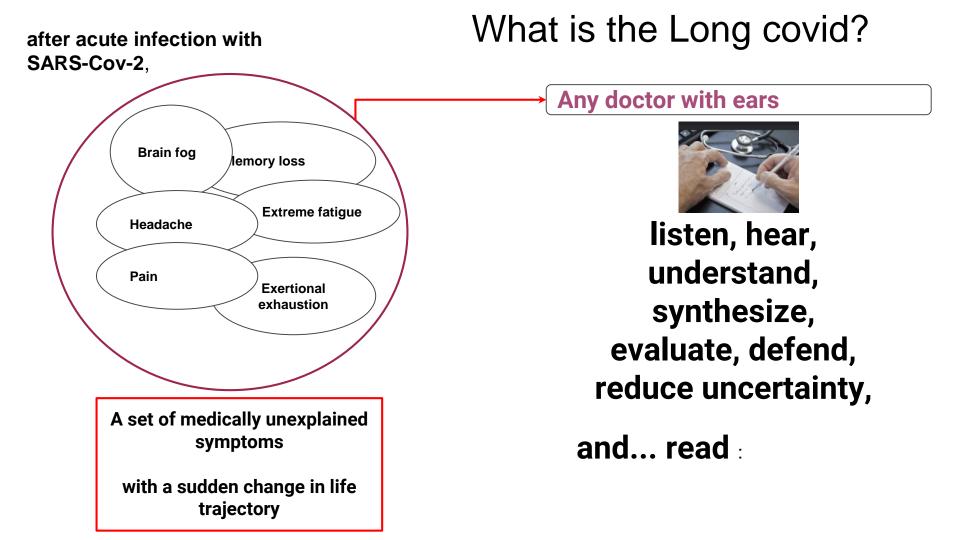
• Patients are often more expert than doctors

but with difficulty discriminating information and accepting uncertainty

• Politicians are absent from the requested number

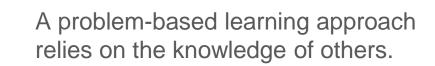
## What is the Long covid?

- the clinician; a set of medically unexplained symptoms, new to the person, occurring after an infection even without Covid 19 symptoms, and including among others; fatigue, exertional exhaustion, respiratory, cardiac, digestive problems, and various and unusual cognitive, memory and neurological disorders.
- the scientist; a chronic Sars Cov 2 virosis, inducing vascular endothelitis, accompanied by platelet micro-aggregates causing localized cerebral or muscular hypoxia associated with multiple autoimmune phenomena.
- **psychiatrist**; burnout or suspicious parents
- the medical adviser; nothing at all, an invention
- the naturopathic or pseudo-scientific doctor: a tremendous economic opportunity
- **politics**: Covid? let's talk about something else!



and read

## Bibliography as a starting point for exploring unknown territories



Master of Santa Clara, **15th century** Death of the Virgin (detail) Lyon museum of fine arts

> Access to open bibliography on Zotero ; https://www.zotero.org/groups/4929325/long\_covid\_open\_library/library

I'm so tired, I'm not myself anymore, I can't run, I can't even walk fast.

I can no longer exert myself, I'm immediately out of breath, as if my chest were being crushed.

I have such a headache, it's like a leaden blanket on my shoulders and it goes up my arm.

my leg moves by itself, my feet sting and sometimes my hands, sometimes it throws so hard.

I have bruises that appear and disappear.

listen to

The bath board would allow me to shower sitting down. So I'm less tired. For the moment, on days when I go to work in the morning, I don't wash in the morning because otherwise I'm too tired to go to work. I don't wash on the days I work. On the other days, I take a bath so I can wash while lying down or sitting up.

Extract from an e-mail received from a 37-year-old patient, teacher, ex-sportswoman, 18th month of Long covid, who wants to apply for disabled administration assistance 16/02/2023

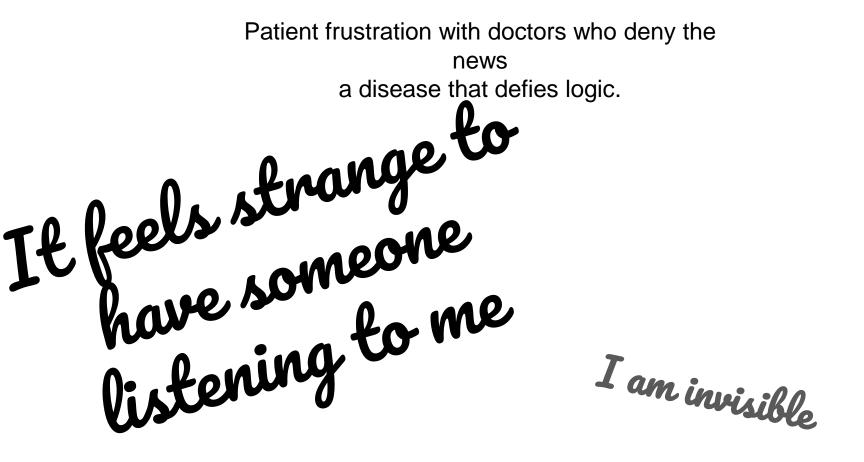
9

listen to

bags of words from 34 patients identified Long Covid, 2022



Jamoulle, M.; Kazeneza-Mugisha, G.; Zayane, A. Follow-Up of a Cohort of Patients with Post-Acute COVID-19 Syndrome in a Belgian Family Practice. *Viruses* **2022**, *14*, 2000. https://www.mdpi.com/1999-4915/14/9/2000



M. Jamoulle. "It feels weird that someone is listening to me' The long Covid in family medicine." Eprint/Working Paper, 2022 (in French only). <u>https://orbi.uliege.be2268/295811</u>.

specialist reports are always the same nothing in pneumo, cardio, neuro, rheumato nothing in conventional organic nothing in conventional imaging

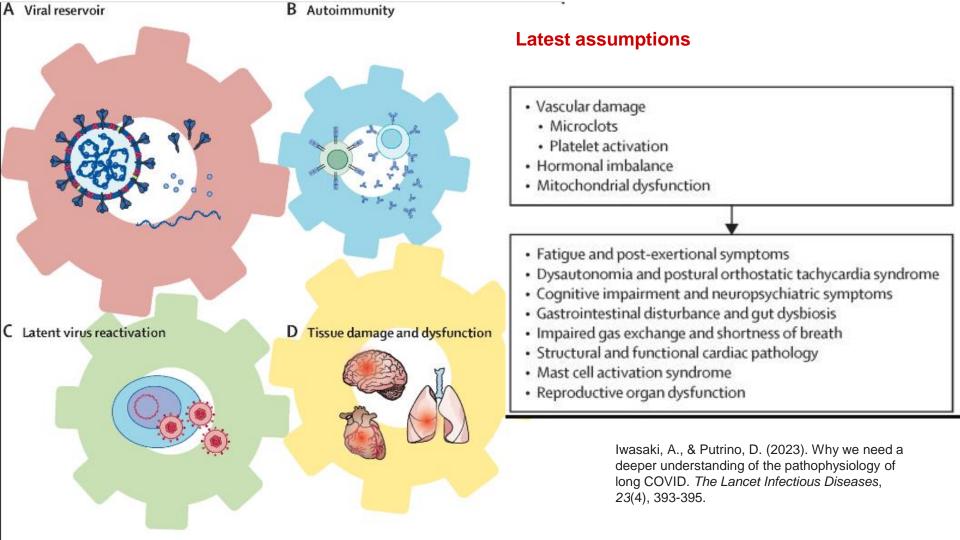


#### diagnostic labels found in wandering patients' files

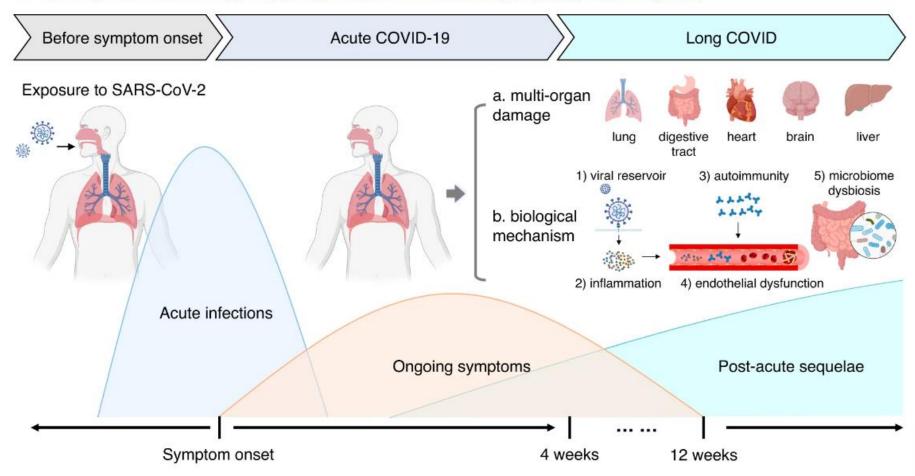
- angor
- Alzheimer's
- pulmonary embolism
- hyperventilation
- fibromyalgia
- traumatic shock
- professional exhaustion
- anxiety attack
- post-traumatic stress disorder
- depression
- lazy teen (a teacher)
- irritable bowel
- functional colopathy
- burnout
- simulation

and therefore the assumptions that reflect the specialty consulted

Rouen MBA. Rome, portal



#### From: The long-term health outcomes, pathophysiological mechanisms and multidisciplinary management of long COVID

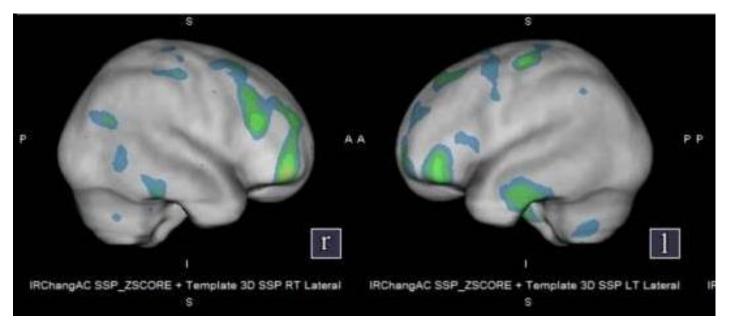


Li, Jingwei, et al. Signal Transduction and Targeted Therapy 8.1 (2023): 416.

#### Technetium scintigraphy (SPECT-CT) in Long Covid patients

Green areas show disturbed blood flow (images obtained by comparing patient images with a reference database) Brain scan. Q-Brain technique.

53 SPECT-CT requested 45 objectivized cerebral flow disorders (here in green) 1 confirmed by PET 5 PET were negative



Male, 47 years old Before acute Covid (10/14/2020); D84 ;D93 ;K84 ;L82 ;P06 ;T82 ;T86 (ICPC-2) ; Post Covid: N71 ; DUSOI 4 ; COOP Charts 24 ; 31 months between acute Covid and diagnosis of long Covid ; MRI normal ; on 09/15/2023 abnormal fatigue, disturbed sleep, burning sensations in legs, loss of words, loss of immediate memory, nausea, difficulty concentrating, claustrophobia, increase in known pain, shortness of breath, recurrent headaches

by courtesy; Dr Salima Bouazza, Hôpital Vésale, Charleroi ISPPC

the database from which I drew the graphs above will also be used

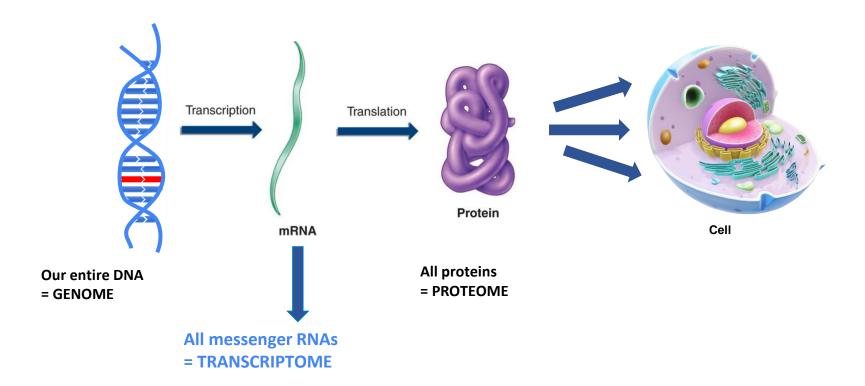
## In search of biomarkers

Thanks to Professor Casanova (Necker and Rockefeller) and the COVID Human Genetic Effort https://www.covidhge.com/

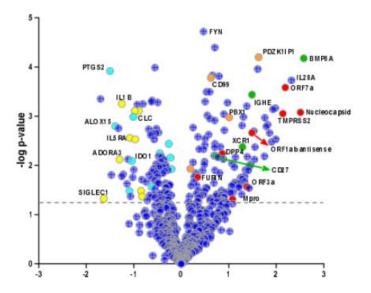
New multi-omics sciences made possible

- transcriptomics (Rega Institute KUL)
- proteomics (UGand and Brodin Lab, Sweden)
  protein research (sNFL)
- genomics (Necker / Casanova)
- cellular neurobiology (Unamur / Nicaise)
- search for platelet micro-aggregates (?)

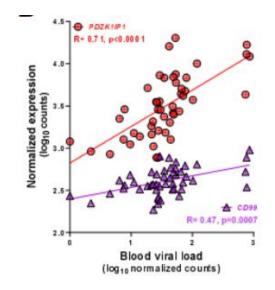
## What is transcriptomics?



Results of transcriptomic analysis - Rega Institute - Prof. Johan Van Weyenbergh - 48 patients (accepted Lancet / Microbe)



Overview of individual data for all SARS-CoV-2 transcripts (expression normalized to numbers) and total blood viral load (sum of all normalized SARS-CoV-2 numbers). Each circle represents a single Long COVID patient (red, n=48) or matched control (green, n=12),



Positive correlation between immune/platelet transcripts (PDZK1IP1, CD99) and viral load (sum of all detectable SARS-CoV-2 transcripts above background), quantified by digital transcriptomics (Spearman correlation, n=48).

# Public health officials in Belgium are not really interested in Long Covid

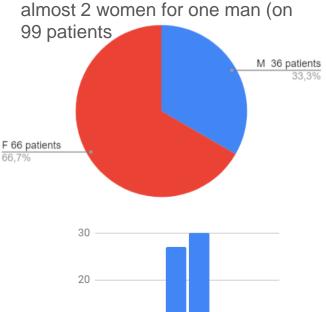
- a pinch of federal expertise center,
- a hint of state's health institute
- a ladle of the national insurer
- nothing from federal ministry of health
- nothing from régional heath authorities
- nothing in research



Calendar. ~1500 (Detail) Leuven, M-Museum

we're having problems with medicine in the face of Long covid

- doctors don't feel concerned
- there are so few general practitioners who want to know
- specialist doctors are nowhere to be seen
- mutual insurers' medical advisors race to get people back to work
- Ministry of health's doctors deny patient
- doctors of occupational diseases have erected insurmountable barriers
- insurance doctors want non-existent evidence



23 34 45 56 68 79 80

average age 40

10

11

training managers are not concerned

## nobody has organized any training Long covid

- Nor universities (except ESP-ULB)
- nor the the family physician associations
- nor any public body



Calendar. ~1500 (Detail) Leuven, M-Museum

## mini bibliography on Long Covid and epistemology

- Au, L., Capotescu, C., Eyal, G., & Finestone, G. (2022). Long covid and medical gaslighting: Dismissal, delayed diagnosis, and deferred treatment. SSM Qualitative Research in Health, 2, 100167. https://doi.org/10.1016/j.ssmqr.2022.100167
- Health misinformation rampant on social media here's what it does and what people can do about it. (2023, December 19). Japan Today.
  https://japantoday.com/category/features/health/health-misinformation-is-rampant-on-social-media-%E2%80%93-here's-what-it-does-why-it-spreads-and-what-people-can-do-about-it
- Kasi, L. S., & Moorthy, B. (2023). A Case Report on Care-Seeking Type Illness Anxiety Disorder after COVID-19 Infection. *Case Reports in Psychiatry*, 2023, 3003499. https://doi.org/10.1155/2023/3003499
- Ledford, H., & Thompson, B. (2024). Audio long read: Long COVID is a double curse in low-income nations here's why. *Nature*. https://doi.org/10.1038/d41586-024-00224-3
- Lyons, M. D., Beekmann, S. E., Polgreen, P. M., & Marschall, J. (2023). What do infectious disease specialists think about managing long COVID? Antimicrobial Stewardship & Healthcare Epidemiology: ASHE, 3(1), e236. https://doi.org/10.1017/ash.2023.519
- Paul, E., Brown, G. W., Ridde, V., & Sturmberg, J. P. (2024). Who is "anti-science"? Public Health in Practice, 7, 100493. https://doi.org/10.1016/j.puhip.2024.100493
- Pietrzak-Franger, M. (2023). Postdigital health practices: new directions in medical humanities. *Medical Humanities*, medhum-2023-012611. https://doi.org/10.1136/medhum-2023-012611
- Sherwood, O. (2023). Hancock's covid inquiry evidence offers few clues as to why long covid was sidelined. BMJ, 383, p2902. https://doi.org/10.1136/bmj.p2902
- Wright, K. A. M., Haastrup, T., & Guerrina, R. (2021). Equalities in freefall? Ontological insecurity and the long-term impact of COVID-19 in the academy. *Gender, Work & Organization, 28*(S1), 163-167. https://doi.org/10.1111/gwao.12518

The needs of patients are immense, but at least in Wallonia there are you https://www.leressort.be/, (In French : le ressort = the spring) thank you



and there's the recent patient association longcovidbelgium@gmail.com