



# 'Long covid' and how medical information is causing illness: A philosophical issue affecting public health

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## KEYWORDS

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Medicine and medical practitioners not only communicate information to individual patients, but also to the broader public to enable sense-making in society in relation to health. Such communication raises its own medical, social and ethical problems. In recent years, scientific research and philosophy have clearly shown that the way individuals make sense of their bodies, and what they perceive as happening to it, can create, modulate, shorten and prolong symptoms, and also influence bodily physiological reactions<sup>1,2</sup> This sense-making is linked to medical philosophy, as philosophy is about the way we conceptualise and understand the world and ourselves. The personal philosophy of patients, the way they conceptualise and act towards their illness, not only affects quality of life; it may affect the health problem itself. So, if health professionals change how patients make sense of their problem by communicating different medical philosophies and narratives, this should also be expected to play a role in processes that influence illness, healing and recovery. In our opinion, this is having an important impact on public health, and raises ethical concerns, particularly in relation to the Covid-19 pandemic, that have received too little attention.

The post-acute covid condition (PACC)—or 'Long COVID'—has become a major public health problem. Whilst medical research is delving into numerous clinical phenomena and biomedical explanations, we believe a broader perspective that includes philosophical reflection will help understanding.

In 2017 Arthur Barsky warned about 'The iatrogenic potential of the physician's words' in a leading medical journal. As a scientist and psychiatrist he highlighted how health professionals can inadvertently amplify and prolong symptoms through the information they convey to patients. This iatrogenic potential, Barsky shows, is

sometimes equivalent to that of drugs.<sup>1</sup> We believe such insights are critically important to understanding conditions such as PACC.

PACC is a poorly defined diagnosis that may encompass a range of clinical conditions and causes that are still under study. We here consider PACC as a syndrome consisting of a multitude of persistent symptoms, including fatigue, in people who initially had mild Covid-19 illness. We posit that medical information, conveyed through public channels including medical journals, newspapers, and social media, likely contributes to this epidemic by inadvertently creating fear, and thus augmenting people's stress response. In particular, the messaging reinforces the expectation that the symptoms are caused by grave bodily damage and will not resolve. In other words, it influences the public's conceptualisation and sense-making of the problem. We believe this does harm and is a public health problem in itself. To the extent that PACC is an iatrogenic problem, we have identified a major ethical issue for the medical profession, as well as an important issue for medical philosophy.

## 1 | PANDEMIC MEETS INFODEMIC

Accompanying the Covid-19 pandemic, we witnessed an explosion in research and public interest in Covid-19 and its sequelae. Information about persistent symptoms after Covid-19 infection spread rapidly (Figure 1). A common theme in this infodemic are countless reports about multiple catastrophic and possibly permanent effects of the virus. This is then coupled with information about a myriad of persistent symptoms that are either linked to a wide range of bodily abnormalities, or presented as mysterious or inexplicable. This leads to unnecessary uncertainty and expectations of permanent disability.<sup>3</sup> A The New York

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**FIGURE 1** What if you never get well from Covid-19? The iatrogenic potential of medical information during the Covid-19 pandemic and beyond (Drawing by Andreas Pahle, MD).

Times title sums the message up: 'What If You Never Get Better From Covid-19?'.<sup>4</sup>

This biomedical story, which links common symptoms to virally induced, permanent damage done to the body's parts is reductionist. We also find good reason to believe that it represents a pathogenic conceptualisation that plays into how people's brains interpret sensations. We know that our brains predict sensations, so symptoms are based on the brain's interpretation about how important or threatening something is to our integrity and wellbeing.<sup>1,2</sup> Thus, the prevailing narrative about danger of permanent damage can lead to self-perpetuating and self-validating cycle of symptom amplification. As Barsky notes: 'Learning that a symptom may be more noteworthy or medically significant amplifies it. Reattributing the symptom to a new and more serious and more concerning source then causes the patient to monitor and scrutinise the symptom more closely, and this heightened attentional focus amplifies the symptom, making it more intense and intrusive, more disturbing and distressing'.<sup>1</sup> What *meaning* the brain—or we—unconsciously and consciously assign to the symptoms is important in determining whether symptoms appear, persist, or disappear.<sup>5</sup> As a corollary, the different medical philosophies that underpin the way we assign meaning to the symptoms are no mere academic trifles: They are causal factors in generating and resolving illness.

## 2 | BIOLOGICAL STRESS RESPONSES

We know that the brain responds to protect us and make us adapt to all challenges of life, from the molecular to the social, by orchestrating physiological stress responses. This happens through the

hormonal hypothalamic-pituitary-adrenal axis and the autonomic nervous system.<sup>6</sup> The results are measurable physiological changes and associated symptoms across many systems, including the brain, heart, lungs, metabolism and immunity. Persistent stress responses can become dysfunctional and cause health problems such as impaired cognition, fatigue, and immune abnormalities, which are all found in PACC. Fear and expectation of permanent disability will feed into the persistence of the stress response.

## 3 | THE DRIVERS OF FEAR

There are at least three drivers contributing to PACC as a partly iatrogenic phenomenon. The first is the biomedical community, which provides the philosophical and empirical contents of the narrative. As could be expected, when reports of lingering symptoms started to appear, biomedicine viewed it in light of the biomedical model, expecting to find explanations and cures in small-scale biological processes (Engel, 1977). The institution of medicine then acted accordingly, scrutinising people's bodies with a wide range of technologies. The result is a huge literature reporting a myriad of abnormalities in multiple systems.<sup>3</sup> There are methodological problems here that include publication bias, inadequate controls and the need for replication. However, in addition, the findings are almost always interpreted in relation to viral specific effects on the organ being studied, and rarely in a wider biopsychosocial perspective that considers patients as sense-making persons whose predictions about the world shape experience itself. The resulting, dominant public narrative is underpinned by standard biomedical



reductionist ontology and epistemology. We believe it should be regarded as potentially pathogenic. It may shape personal and public perceptions that modulate the illness itself. As an example of the power of such effects, a recent qualitative study of 14 persons having recovered from very severe myalgic encephalopathy/chronic fatigue syndrome, which is very similar to PACC, found a common experience: a profound shift in their conceptualisation of the problem was linked to their recovery. This shift was from being the victim of unchangeable biomedical disease to 'a more complex view of causality and illness and a new sense of self-agency'.<sup>7</sup> Previous research has shown that the belief that the problem is caused by a physical defect (i.e., a standard biomedical conceptualisation) is associated with poor prognosis.<sup>8</sup>

The second driver is the mass media reporting on these studies with an underlying message that recovery is uncertain, and the condition may be life-long; illustrated by distressing personal stories, while patients who recover are largely ignored.<sup>4</sup>

The third driver are patient campaign groups operating mainly through social media. They share their own symptoms, experiences, and fears along with newspaper stories and medical articles. The 'Long Covid' patient narrative has merged with chronic fatigue syndrome or ME (CFS/ME) advocacy. This states that this is a 'biomedical disease', nothing "psychological" is causing it, activity is dangerous, many will never recover. These groups crack down on any mention of a biopsychosocial approach, portraying this narrative as 'gaslighting' patients.

## 4 | HOW TO ADDRESS THE PROBLEM

We conclude that different forms of medical information about PACC, underpinned by different medical philosophies, likely influence the way our brains consciously and unconsciously predict and interpret symptoms. This in turn produces, amplifies, diminishes, or resolves the symptoms. Although space does not permit a thorough review, a literature is emerging to support this biopsychosocial hypothesis, including data that anxiety, worry and perceived stress increases the risk.<sup>9</sup> A recent Norwegian study showed half with adolescents with PACC as defined by WHO had never been infected with Covid-19, pointing us towards other causes than the virus itself; and a theoretical model using Bayesian approaches concluded that the constant messaging of irreversible tissue damage as a cause of Long Covid is 'predisposing, precipitating and perpetuating' factors for the syndrome.<sup>10,11</sup>

What can be done? This article illustrates how the framing of post-covid condition by mainstream medicine may actually be contributing to the illness. Through its actions and words, mainstream medicine may be contributing to the production and the persistence of symptoms, and thus be a iatrogenic factor. We first need mainstream medicine to acknowledge the possibility that these mechanisms are at play. Then, changing the narrative about and conceptualisation of the symptoms, is part of the solution. As Barsky notes, merely explaining to people how nocebo responses and stress may create and prolong symptoms may help.<sup>1</sup>

This scientifically informed narrative needs to explain and normalise how symptoms and physiological changes are produced in the body in a social and environmental context. This includes the relationships and influences between the brain, the rest of the body, thoughts, expectations, and perceptions. Importantly, we need to include the experiences of people that have recovered in shaping research and the narrative about the illness.<sup>12,13</sup> Available biomedical findings must also be interpreted in light of a broader explanatory framework appropriate for conditions with persistent symptoms. The matter is urgent, both in terms of public health and professional ethics.

## REFLEXIVITY STATEMENT

HV has worked in general practice, public health and medical ethics. He is the former leader of Recovery Norway, and organisation consisting of people who have experienced recovery from post-viral syndromes and other illness commonly labelled "medically unexplained". PG is a medical epidemiologist who has worked in evidence synthesis in infectious disease for 30 years, with personal experience of post-covid syndrome, who recovered using psychological approaches and physical activity.

## CONFLICT OF INTEREST STATEMENT

The authors declare no financial conflicts of interest.

## DATA AVAILABILITY STATEMENT

Not applicable. It is a commentary, philosophical argument.

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