COVID-19 and the creation of a new disease

Disease is more than purely biological. Chemical imbalances, hormone deficiencies, and micro-organisms are filtered through the human experience to create the phenomenon we call a disease. As Charles Rosenberg wrote in his essays on this subject:

'In some ways disease does not exist until we have agreed that it does, by perceiving, naming, and responding to it.'[1]

Rosenberg argued that patients, families, clinicians, charities, hospitals, professional bodies, insurers, employers, the media, and the government all frame biology in a way that both makes sense to and benefits them.

Working for the last couple of months as a GP in one of the 'hot hubs' in North London, Rosenberg's words resonated with me as I watched the emergence of a new disease in exactly the way that he predicted. COVID-19 was framed by the experiences of patients and doctors and the interplay between the media and the changing policies from the NHS and government. What was also apparent was that the frame was shifting from week to week.

In the early weeks of the crisis I was working in the overwhelmed 111 setting.[2] The government was concentrating on protecting the NHS and the messaging was focused on staying at home. The primary care concern was on how to triage safely[3] and manage as many people at home as possible. The doctors working on the phones framed the disease as an acute illness. Once a patient had passed week 2 the danger was felt to be over and hospitalisation unlikely.

COVID-19 IS A CHRONIC ILLNESS

After a couple of weeks in the hot hub the frame shifted. The first pulmonary emboli[4] and fibrotic lung changes[5] began to be seen weeks after the initial illness. The respiratory teams at the local hospitals became involved and took ownership. Clinics were set up and the disease became re-framed as a chronic respiratory issue. We saw a corresponding spike in referrals to the hot hub with chest pain and breathlessness coupled with a similar spike of referrals from us into the hospital. Only two of the patients we referred had thrombotic disease; neither was felt to be COVID-19 related.

Then there was the news in the press[6] as well as an emailed alert to all GPs[7] highlighting the small number of children suffering from a Kawasaki-like illness.[8] In the minds of both the public and of GPs the disease frame shifted again, from being a disease of older people to be a potentially life-threatening childhood illness. We saw a corresponding spike of referrals both to the hub and to A&E; no significant COVID-19 illnesses were diagnosed.

More recently, patients began presenting with severe fatigue weeks after the initial infection and persisting in some cases for over 2 months. Little mentioned in the literature, this has been widely reported by patients. Online support groups have been set up to both help with the symptoms and gather data.[9] Recognition of this has led to another shift towards GPs and patients framing COVID-19 as a chronic illness.

The reality is that COVID remains most dangerous in the early stages, as was initially shown in the data from China.[10] It is also more hazardous to people with certain characteristics.[11] As has happened throughout the history of medicine, the disease that is being created in the minds of some patients and doctors sometimes seems to bear little relationship to these biological facts.

DEFINING THIS NEW DISEASE

We must recognise that as clinicians we are involved in creating a new disease. According to Rosenberg's structure we have 'perceived' and 'named' it, and are now in the process of bringing it into existence by our collective response. It is this step that is critical. We must be conscious that the way that we communicate symptoms and risk with each other and our patients has wider implications beyond the immediate clinical situation. Our human response to this new biological challenge is what will define this new disease for years to come.

"... the disease that is being created in the minds of some patients and doctors sometimes seems to bear little relationship to [the] *biological facts."*

James Hibberd,
GP, Islington, North London.
Email: james.hibberd@nhs.net

This article was first posted on *BJGP Life* on 12 June 2020: https://bjgplife.com/2020/06/12/covid-19-and-the-creation-of-a-new-disease/

DOI: https://doi.org/10.3399/bjgp20X712013

REFERENCES

1. Rosenberg C, Golden J, eds. *Framing disease: studies in cultural history.* New Brunswick, NJ: Rutgers University Press, 1992.
2. Roberts M. Coronavirus: NHS 111 has 1.7 million queries in 15 days. *BBC* 2020; **1 Apr:** https://www.bbc.co.uk/news/health-52120804 (accessed 24 Jun 2020).
3. Greenhalgh T, Koh GCH, Car J. Covid-19: a remote assessment in primary care. *BMJ* 2020; **368:** m1182.
4. News. News Analysis. Covid-19 and thrombosis: what do we know about the risks and treatment? *BMJ* 2020; **369:** m2058.
5. Comment. Pulmonary fibrosis secondary to COVID-19: a call to arms? *Lancet Respir Med* 2020; DOI: https://doi.org/10.1016/ S2213-2600(20)30222-8.
6. Roberts M. Coronavirus alert: rare syndrome seen in UK children. *BBC* 2020; **27 Apr:** https://www.bbc.co.uk/news/health-52439005 (accessed 2 Jul 2020).
7. Philpotts E. GPs alerted to 'coronavirus-related' condition emerging in children. *Pulse* 2020; **27 Apr:** http://www.pulsetoday.co.uk/clinical/clinical-specialties/respiratory-/gps-alerted-to-coronavirus-related-condition-emerging-in-children/20040689.article (accessed 2 Jul 2020).
8. Riphagen H, Gomez X, Gonzalez-Martinez C, *et al.* Hyperinflammatory shock in children during COVID-19 pandemic. *Lancet* 2020; **395(10237):** 1607–608. https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)31094-1/fulltext#%20 (accessed 2 Jul 2020).
9. COVID-19 Prolonged Symptoms Survey — Analysis Report. What does COVID-19 recovery actually look like? An analysis of the prolonged COVID-19 symptoms survey by patient-led research team. 2020.
10. Wu Z, McGoogan JM. Characteristics of and important lessons from the coronavirus disease 2019 (COVID-19) outbreak in China: summary of a report of 72 314 cases from the Chinese Center for Disease Control and Prevention. *JAMA* 2020; DOI: 10.1001/jama.2020.2648.
11. Public Health England. *COVID-19: review of disparities in risks and outcomes.* 2020.