Learning from Long COVID: How Healthcare Needs to Change for Contested Illnesses

Authors: David Tennison

Abstract: In the wake of the Covid-19 pandemic, a new chronic illness emerged onto the global stage: Long Covid. Long Covid presents with several symptoms commonly seen in other poorly-understood illnesses, such as fibromyalgia (FM) and myalgic encephalomyelitis/ chronic fatique syndrome (ME/CFS). However, while Long Covid has swiftly become a recognised illness, FM and ME/CFS are still seen as contested, which impacts patient care and healthcare experiences. This study aims to examine what the differences are between Long Covid and FM; and if the Long Covid case can provide guidance for how to address the healthcare challenge of contested illnesses. To address this question, this study performed comprehensive research into the history of FM; our current biomedical understanding of it; and available healthcare interventions (within the context of the UK NHS). Analysis was undertaken of the stigma and stereotypes around FM, and a comparison made between FM and the emerging Long Covid literature, along with the healthcare response to Long Covid. This study finds that healthcare for chronic contested illnesses in the UK is vastly insufficient - in terms of pharmaceutical and holistic interventions, and the provision of secondary care options. Interestingly, for Long Covid, many of the treatment suggestions are pulled directly from those used for contested illnesses. The key difference is in terms of funding and momentum - Long Covid has generated exponentially more interest and research in a short time than there has been in the last few decades of contested illness research. This stands to help people with FM and ME/CFS - for example, research has recently been funded into "brain fog", a previously elusive and misunderstood symptom. FM is culturally regarded as a "women's disease" and FM stigma stems from notions of "hysteria". A key finding is that the idea of FM affecting women disproportionally is not reflected in modern population studies. Emerging data on Long Covid also suggests a slight leaning towards more female patients, however it is less feminised, potentially due to it emerging in the global historical moment of the pandemic. Another key difference is that FM is rated as an extremely low-prestige illness by healthcare professionals, while it was in large part due to the advocacy of affected healthcare professionals that Long Covid was so quickly recognised by science and medicine. In conclusion, Long Covid (and the risk of future pandemics and post-viral illnesses) highlight a crucial need for implementing new, and reinforcing existing, care networks for chronic illnesses. The difference in how contested illnesses like FM, and new ones like Long Covid are treated have a lot to do with the historical moment in which they emerge - but cultural stereotypes, from within and without medicine, need updating. Particularly as they contribute to disease stigma that causes genuine harm to patients. However, widespread understanding and acceptance of Long Covid could help fight contested illness stigma, and the attention, funding and research into Long Covid may actually help raise the profile of contested illnesses and uncover answers about their symptomatology.

Keywords: long COVID, fibromyalgia, myalgic encephalomyelitis, chronic fatigue syndrome, NHS, healthcare, contested illnesses, chronic illnesses, COVID-19 pandemic

Conference Title: ICHCD 2024: International Conference on Healthcare and Chronic Diseases

Conference Location : Venice, Italy Conference Dates : April 04-05, 2024