Post-COVID-19 syndrome (long-COVID)

Michael Sharpe MA MD FRCP FRCPsych
Professor of Psychological Medicine

University of Oxford & Oxford University Hospitals
February 2021
What is post COVID syndrome?
NICE Definitions of COVID related illness

- **Acute COVID-19**: signs and symptoms of COVID-19 for up to 4 weeks.

- **Ongoing symptomatic COVID-19**: signs and symptoms of COVID-19 from 4 to 12 weeks.

- **Post-COVID-19 syndrome**: signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis (Long COVID).
Beware of **poor quality research** with unclear denominators
Who gets Long COVID?

• Five to ten percent of patients at 3 months
  – Wide range of estimates
  – Little long term follow up and selected samples

• Older patients

• Females

• Pre-morbid vulnerability
The post-COVID clinic in Oxford

• Sees patients post-hospitalisation and also GP referrals

• Multidisciplinary: hospital clinic and community rehabilitation
  – Respiratory
  – Rehabilitation
  – Psychiatry
  – Psychology
  – Physiotherapy
  – Plus virtual MDT

• Based on NICE guidelines (and short-term funding)
Case study from the post-COVID clinic.

- 35 year old woman referred by her GP
- Teacher with 3 small children
- ‘COVID like’ illness - not hospitalized - six months ago
- Now disabling fatigue made worse by exertion, aches shortness of breath and heaviness in chest. Anxious.
- Unable to work
Symptoms of post-COVID Syndrome

- Low vision - 17%
- Red eyes - 10%
- Vertigo - 6%
- Fatigue - 53%
- Muscle pain - 6%
- Lack of appetite - 8%
- Diarrhoea - 3%
- Skin lesions - 7%
- Joint pain - 27%
- Headache - 9%
- Rhinitis - 13%
- Loss of/changed sense of smell - 15%
- Sjögren's syndrome - 14%
- Loss of/changed sense of taste - 10%
- Sore throat - 7%
- Cough - 16%
- Chest pain - 22%
- Shortness of breath - 43%

Employment status of 100 patients seen in Post COVID clinics at 6 months

From the data available, 25% of patients had not returned to work due to extent of symptoms.
What causes post COVID syndrome?
We must not assume that post COVID syndrome is a single condition with a single cause.
Biological Factors

- Damage to lung, other organs and immune abnormalities
- (Reversible) dysfunction e.g. autonomic nervous system
- Effects of coping behaviour e.g. resting, abnormal breathing
Multi-symptom illness does not necessarily mean multi-system pathology
Psychological Factors

• Seeing bodily sensations as alarming and focussing on them

• Becoming anxious and then experiencing more symptoms (significant anxiety in a high proportion of patients)

• Coping including avoidance and seeking medical care
Social factors - The media

“In some cases, long COVID could mean lifelong COVID. The effects can be horrible. Among them are lung damage, heart damage and brain damage that can cause memory loss and brain fog, kidney damage, severe headaches, muscle and joint pain, loss of taste and smell, anxiety, depression and, above all, fatigue. We should all fear the lasting consequences of this pandemic”. 

George Monbiot, The Guardian, January 2021
Social factors – Support groups

Long Covid Support Group

Doctors & Long - COVID Support Group

NEW Long Covid Support Group for North West Leicestershire

Registration for Long - COVID Group
These patients are just so frustrated,” he says. “Their physicians don’t believe them and so they get psych referrals. Just to be able to tell these people they have a real disease and here’s what’s causing it — that would be really meaningful.”

An immunologist (reported in Nature)
Summary of possible causes of Post-COVID syndrome

**Biological**
- Organ pathology and immunology
- Physiological changes such as dysautonomia

**Psychological and behavioural**
- Fear, focussing on symptoms anxiety and depression
- Coping behaviour

**Social**
- Misinformation/ online and press and iatrogenesis
- Social, interpersonal and employment issues
How can we treat post COVID syndrome?
We need to balance ‘keeping an open mind’ with a pragmatic approach to management.
Basic Management

• Patients need to feel listened to and believed

• Physicians must manage uncertainty

• Identify and treat what is treatable (medical and psychiatric)

• Give a positive message

• Rehabilitation
There are similarities with other illnesses such as **Chronic Fatigue Syndrome (CFS/ME)**
Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial

Prof PD White, MD, MPH, AL Johnson, PhD, L Potts, MSc, R Walwyn, MSc, JC DeCesare, BSc, HL Baber, BSc, M Burgess, PhD, LV Clark, PhD, DL Cox, PhD, J Bavington, BSc, BJ Angus, MD, G Murphy, MSc, M Murphy, FRCP, H O’Dowd, PhD, D Wilks, FRCP(Ed), Prof P McCrone, PhD, Prof T Chalder, PhD*, Prof M Sharpe, MD*, on behalf of the PACE trial management group1
At present the best treatment is psychologically informed rehabilitation
Challenges in providing rehabilitation
What is the outcome of post COVID syndrome?
Outcome of Long-COVID

• Most improve - but it may be slow

• Explanation and rehabilitation seem to be helpful

• We don’t have much data – but the rule of thirds seems likely

• Reasonable guess is one percent will have long term disability – but will depend in part on care received.
Case study from the BMJ

• Middle aged Professor of Medicine - Paul Garner

• ‘COVID like’ illness - not hospitalized

• Disabling fatigue made worse by exertion, aches shortness of breath and heaviness in chest. Anxious and depressed. “ME”

• Unable to work

• Recovered with rehabilitation
Summary

• Beware of poor quality research with unclear denominators
• We must not assume that post COVID syndrome is a single condition with a single cause
• Multi-symptom illness does not necessarily mean multi-system pathology
• We need to balance ‘keeping an open mind’ with a pragmatic approach to management
• There are similarities with other illnesses such as Chronic Fatigue Syndrome (CFS/ME)
• At present the best treatment is psychologically informed rehabilitation
• There is likely to be some long-term disability
References

• NICE COVID-19 rapid guideline: managing the long-term effects of COVID-19; 18th Dec 2020


Thank you

Michael Sharpe@stx.ox.ac.uk