MACIVER, E., ADAMS, N.N., KENNEDY, C., DOUGLAS, F., SKÅTUN, D., HERNANDEZ SANTIAGO, V., TORRANCE, N. and GRANT, A. 2022. *Living with long COVID: the problem of lack of legitimation*. Presented at the 2022 Annual conference of the British Sociological Association Medical Sociology Study Group (BSA MedSoc 2022), 14-16 September 2022, Lancaster, UK.

Living with long COVID: the problem of lack of legitimation.

MACIVER, E., ADAMS, N.N., KENNEDY, C., DOUGLAS, F., SKÅTUN, D., HERNANDEZ SANTIAGO, V., TORRANCE, N. and GRANT, A.

2022

Living with long covid – the problem of lack of legitimation

Dr Emma MacIver, Research Fellow - Robert Gordon University

Emma MacIver, Nicholas Norman Adams, Catriona Kennedy, Flora Douglas, Diane Skåtun, Virginia Hernandez Santiago, Nicola Torrance*, Aileen Grant*

* Joint principle investigators

LoCH
Long Covid in Health Workers

SCHOOL OF NURSING, MIDWIFERY AND PARAMEDIC PRACTICE

CHIEF SCIENTIST OFFICE

ROBERT GORDON UNIVERSITY ABERDEEN

1495 UNIVERSITY OF ABERDEEN

University of St Andrews

Structure and aims of the presentation

- Overview of study of Long Covid in Health Workers (LoCH) study.
- Brief summary of relevant elements of Parsonian concept of the sick role, particularly legitimation.
- Consideration of legitimation in relation to the study findings: Why is legitimation so complex in the context of Long Covid? Why is legitimation important? What are the implications of a lack of legitimation? Why legitimation goes beyond a diagnosis.

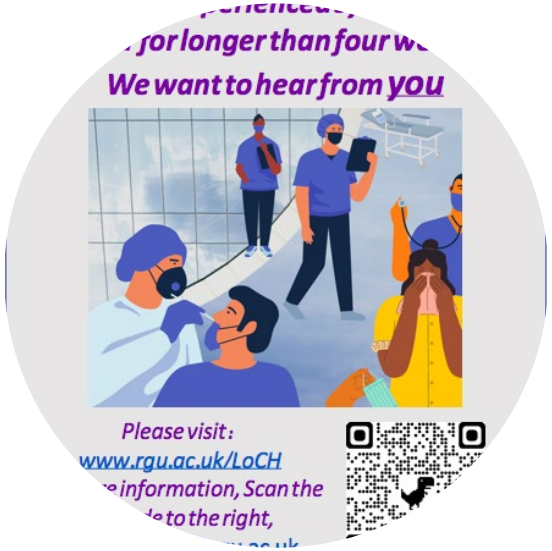
Brief overview of Long Covid in Health Workers study

Aim - to establish the nature and extent, and impact of long covid* on the health and well-being of NHS workers in Scotland *and* determine the longer-term effects of Covid-19 on personal and working lives, self-management strategies, use of healthcare resources and any unmet health care needs.

*Long covid includes both ongoing symptomatic COVID-19 (4 to 12 weeks) as well as post-COVID-19 syndrome (over 12 weeks).

Longitudinal, mixed methods approach – targeted NHS workers from across Scotland. Survey (471) and follow-up semi-structured interviews with 50 participants (medics, nurses, AHPs, ancillary), repeated after 6 months.

Participants symptoms and course of illness varied in terms of severity and duration. Very often severe, debilitating and unpredictable symptoms affecting multiple bodily systems. Often had to suspend/ modify normal roles and functions, in terms of work, home and family responsibilities.

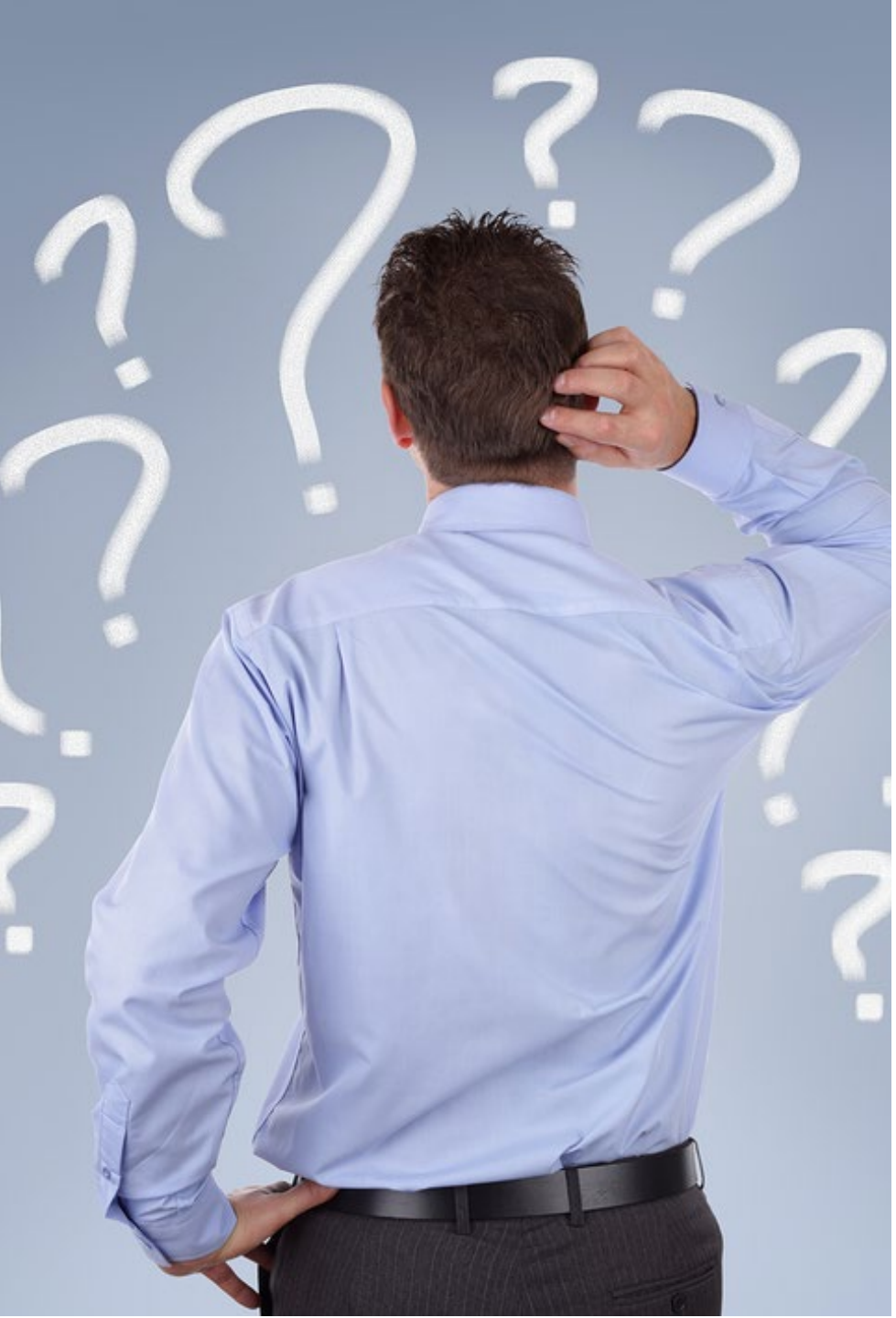


The relevance of Parsons ‘Sick Role’ theory

- Parsons (1951), illness = deviant state, requiring the adoption of the ‘sick role’
- Rights, exemptions and responsibilities – to recover and minimise disruption, to restore order in society.
- Requires external validation or legitimation from medic, entered into with a diagnosis.
- Parsons sick role theory has been heavily disputed – paternalistic assumptions, patient as passive, less applicable to chronic illness (e.g. Frank, 2016; Vassiley et al, 2017, Knight et al, 2018).
- BUT, dismissing the sick role theory outright risks overlooking critical aspects which may be relevant today (Varul, 2010; Hallowell et al, 2015; Williams, 2005).
- Other key work around sick role and chronic illness includes – e.g. Crossley (1998) – HIV, Glenton (2003) – chronic back pain, and Cheshire et al, (2020) – ME/CFS.
- Legitimation of Long Covid s complex and problematic. Long Covid was not necessarily diagnosed or recognised by their GP (or other medical professional), or appropriate testing, referrals or support offered, even where symptoms were severe and limiting.

Legitimation of Long Covid – the complexities of diagnosis and recognition

- Diagnosis - central to the process of legitimation, yet accessing a diagnosis of Long Covid was not straightforward.
- *…there is no certainty but actually giving something a name can be quite helpful. It doesn't make it go away…but it validates that actually what you're having isn't normal…*
- Just over half (28) had a diagnosis of Long Covid, though often vague - *possible/ presumed/ probable* Long Covid (13).
- *…the clinical symptoms, the background sounded like COVID, so we, we presumed long COVID from kind of October onwards.*
- 22 – no diagnosis of Long Covid/ had never had their Long Covid acknowledged by their GP or other medical professional.
- In most cases, diagnosis (or probable diagnosis) was made by GP before (or without) referrals for further testing. In others, it was assigned by a specialist/ consultant (5).
- Majority of sample = medics/ nurses/ HCPs with clinical knowledge and networks/ contacts in healthcare – but not always a diagnosis or recognition of their Long Covid, or further follow-up.



Legitimation of Long Covid – the complexities of diagnosis and recognition

Attaining a diagnosis/ recognition of Long Covid was problematic due to several factors:

1. Testing issues – i. no specific test for Long Covid, basis of exclusion, may yield normal/ inconclusive results. ii. . Reluctance to diagnose Long Covid in the absence of a positive covid test.

2. Presentation of symptoms - symptoms may be less visible, relapsing-remitting, overlap or suggestive of other conditions.

3. The 'novelty' of the condition – and lack of knowledge around Long Covid. *My GPs very nice but doesn't have much to offer and always asks me if I've got any ideas of anything.*

4. Relationship with GP and access issues - difficulties accessing GP and other health care professionals during pandemic. Those most likely to have had their Long Covid recognised or diagnosed reported: having a positive and collaborative relationship with their GP, face-to face contact with GP, continuity of carer (GP).

5. Misdiagnosis – depression, anxiety or other possible causes for symptoms.

- *I think there's quite often a jump to provide like a kind of psychological explanation for their symptom, the symptoms people with long covid are having…one GP I spoke to, the first thing she said to me response to my symptoms was like, basically, are you sure you're not depressed…she screened me for depression…I don't think there's a very good understanding that actually, we have a chronic physical disability.*

- *If I haven't Long Covid, what have I had. There was a period of a few months where I was quite convinced I had MS, it took me to places I've never had to go before.*

The implications of lack of legitimation of Long Covid

1. <u>Unable to fully take on a 'sick role'</u>

- All recognised their Long Covid themselves, expressed a clear desire to recover and were motivated to do so.
- Individuals wanted their symptoms and experiences to be recognised, many wanted these to be investigated and treated, but often felt dismissed.
- 36/ 50 working in some capacity - some felt unable to take time off work, felt or like a *'fraud'*, or lack of understanding from others.

The implications of lack of legitimation of Long Covid

2. <u>Less likely to access further testing or referrals in absence of acknowledgement or diagnosis of Long Covid</u>

- 24 (out of 28) with a diagnosis of Long Covid (or probable Long Covid) had had further tests or been referred to specialists, compared to 8 (out of 22) without a diagnosis.
- Differences in type and number of referrals, included: haematology; respiratory; cardiology; ENT; chronic pain; rheumatology; neurology; physio; rehab consultant; OT; CBT; chronic pain clinic; renal consultant.
- 18 – had not had referrals to secondary care. Access to other care not always required – e.g. mild symptoms or little that could be done about specific symptoms (e.g. loss of taste or smell). Others felt dismissed by their GP and had not pursued: *…and the GP told me to get on with it, there's nothing you can do…and I just thought, you know what, what's the point.*
- Importance of appropriate and timely referrals or treatment emphasised by participants.

On it’s own, diagnosis of Long Covid is not enough…

Merely a Long Covid diagnosis is not suffice in terms of meaningful help or support to address symptoms or recovery.

- There has to be recognition, acknowledgement and understanding of individual’s symptoms, concerns and impacts.
- Appropriate and timely referrals to specialists and other support services.
- Need to be listened to - on it’s own, being listened to had therapeutic benefits for some.
- Recognition of and learning from the individual’s expert knowledge and position.
- *finding out…what is important to them? What do they want to achieve in an ideal world? Just having that listening ear and letting them tell you.*
- A co-ordinated approach to follow-up testing and care.
- ‘Meaningful legitimation’.

Summary and Conclusions

Despite criticisms of the 'Sick Role' theory, this provides a useful means to understand the experience of legitimation of Long Covid in relation to the 'Long Covid in Health Workers' study. The findings revealed a complex picture where Long Covid was not always recognised, acknowledged or diagnosed, appropriately investigated or treated, even where symptoms were severe.

Possible explanations for this include: testing issues and presentation of symptoms; novelty of the condition; lack of access to and relationship with GP; and misdiagnoses. Significant in being able to legitimately take on a sick role, without feelings of guilt or suspicion from others, over work absence or necessitated changes at work, as well as access to further care and understanding from others.

Whilst recognition or diagnosis of Long Covid is at the heart of legitimation, support in managing symptoms and moving toward (some degree) of recovery goes beyond just a diagnosis, to more 'meaningful legitimation', that is recognition, acknowledgement and understanding of the condition and its impacts, a timely and appropriate response, and acknowledgement of patient as partner and expert in their needs and care.

Thank You!