

AUT CENTRE FOR PERSON CENTRED RESEARCH



Psychosocial experiences of Long Covid

Professor Nicola Kayes



Long COVID: Journeying together through the fog symposium, May 2022

The making of Long Covid: from individual to collective narratives

"There are strong reasons to argue that Long Covid is the first illness to be made through patients finding one another on Twitter and other social media.."

Callard & Perego (2021)

RESEARCH ARTICLE

Persistent symptoms after Covid-19: qualitative study of 114 "long Covid" patients and draft quality principles for services

Emma Ladds¹¹, Alex Rushforth¹¹, Sietse Wieringa¹, Sharon Taylor^{2,3}, Clare Rayner⁴, Laiba Husain¹ and Trisha Greenhalgh¹

Abstract

Background: Approximately 10% of patients with Covid-19 experience symptoms beyond 3-4 weeks. Patients call this "long Covid". We sought to document such patients' lived experience, including accessing and receiving healthcare and ideas for improving services.

Methods: We held 55 individual interviews and 8 focus groups (n = 59) with people recruited from UK-based long Covid patient support groups, social media and snowballing. We restricted some focus groups to health professionals since they had already self-organised into online communities. Participants were invited to tell their stories and comment on others' stories. Data were audiotaped, transcribed, anonymised and coded using NVIVO. Analysis incorporated sociological theories of illness, healing, peer support, clinical relationships, access, and service redesian.

Results: Of 114 participants aged 27-73 years, 80 were female. Eighty-four were White British, 13 Asian, 8 White Other, 5 Black, and 4 mixed ethnicity. Thirty-two were doctors and 19 other health professionals. Thirty-one had attended hospital, of whom 8 had been admitted. Analysis revealed a confusing illness with many, varied and often relapsing-remitting symptoms and uncertain prognosis; a heavy sense of loss and stigma; difficulty accessing and navigating services; difficulty being taken seriously and achieving a diagnosis; disjointed and siloed care (including inability to access specialist services); variation in standards (e.g. inconsistent criteria for seeing, investigating and referring patients); variable quality of the therapeutic relationship (some participants felt well supported while others felt "fobbed off"); and possible critical events (e.g. deterioration after being unable to access services). Emotionally significant aspects of participants' experiences informed ideas for improving services.

Conclusion: Suggested quality principles for a long Covid service include ensuring access to care, reducing burden of illness, taking clinical responsibility and providing continuity of care, multi-disciplinary rehabilitation, evidencebased investigation and management, and further development of the knowledge base and clinical services. (Continued on next page)



The contested meaning of "long COVID" - Patients, doctors, and the politics of subjective evidence

Phillip H. Roth ", Mariacarla Gadebusch-Boadio"

¹ EWHF Andret Unternity, Kan Hanksopp Kalog, Uniters of Research, Deameter 75, 12082, Andres, Germany ¹ Determing Program Rese, Institute Jor Medical Humanitity, Visualisep Cooput J, 80127, Brin, Dermany

ARTICLEINPO

In our article, we recomment have the patient made inco "long COVD" was able to become a widely account encoupt in patier discusses. While the resultion was latitly includer to the patier we, we show here the
and along it all application relations states. Les de dissolutions of appen sign de differente sequentes and appendieurs and appendieurs de la construction de management de management appendieurs de la construction de la

L. Introduction

The distinuition "issue COVEP" has easined increasing tracun possilensie, However, both the tivity the workhold somewhing of these affected and the repo-instruintion of reports on the mobleculy endering symptoms of nme and the condition itself are controvertaid. Putients suffering from ong COV/D, senally in the alternath of an infection, experience 'a pain, fatigue, shortness of breath, and cognitive dystruction, and the idlamation, tendors, and advancedy ("Jacon et al., 2027-16). It experiment and a conclusion on the same "long OVE" has thus here a long of the resultion in the second of the solution of the JOYD 19, are ables not tested, size on ne water or researce, see elses in diagnostic linds. Reliable and accounte diagnosis is a misentisti-of data solutions associates as is secriblar appropriate care and (W190) pr



Research pape Characterizing long COVID in an international cohort: 7 months of symptoms and their impact

Barnah E. Davis^{4,1}, Gina S. Assaf^{4,1}, Lisa McCorkell^{4,1}, Hannah Wei^{4,1}, Ryan J. Low^{4,4,1}, Yochai Re'em^{4,4,2}, Signe Redfield⁴, Jared P. Asstin^{4,1}, Athena Akram^{4,6,1,4}

Open Access

Eine

Seywords Long Could Post-acute Covid-19 syndrome

Conid-19

Nanutive medicine

Online communities Health social movem

ABSTRACT ARTICLE INFO

Anno ar Anno 2011 Reconstruit 2 April 2621 Recipital 18 Senio 2021 Annophil 21 Senio 2021 Annophil 21 Senio 2021 Annophil 21 Senio 2021 Krywords Long (DHD) Post accir Topalian of Fatherin Gall crossed COMID-Init COMID-Init COMID-Init company COMID-IN-Init Past COMID-IN-Init Past COMID-IN-Init Past COMID-IN-Init Past COMID-IN-Init Past COMID-IN-INIT

Authors, Published by Elsevier 114, This is an open access article andre the CE-Ry lives



Contents lists available at ScienceDirect

Long Covid - The illness narratives

Alex Rushforth 1, Emma Ladds 1, Sietse Wieringa , Sharon Taylor . Laiba Husain , Trisha Greenhalgh

⁶ Nufföld Department of Primary Care Health Sciences, Lintersity of Oxfard, Oxfard, OK2 605, UK ⁹ Control and Nee'h Wasz London NYE Provadation True, Unland Kingdom ⁹ Imperial College School of Medicine, London, United Kingdom

ARTICLE INFO ABSTRACT



1. Introduction

In May 2020, two months after the Covid-19 pandemic was declared, the British Medical Journal published a patient blog (Go 20201. The author, a doctor himself, described still Seeling 'weisd as hell' six weeks after contracting unpected Covid-19, despite official advice stating that the typical recovery period for 'mild' (by which was meant non-hospitalized) cases was around two weeks. His was not the first account of Covid-19's persisting symptoms, but it was probably the first to be picked up by the medical and mainstream oreas. Soon after, numerous similar stories appeared in mainstream media, social media and podcass, describing the lived experience of more prolonged Covid-19. Patients described many, varied and fluctuating symptoms

experiences and campaigned to mise awareness, influence guidelines and service models, and coattribute to research. In this paper, we explore long Covid's rapid emergence and unique status among illnesses, using a dataset of marrative interviews and focus groups with people with long Covid. In a previous paper, we reported what these people talked about (Ladds et al., 2020b), here we analyze

WHEY

Chilard, Deford, UK

Dr Denna Ladris

Exploring invisibility and epistemic injustice in Long Covid-A citizen science qualitative analysis of patient stories from an online Covid community

Jane Ireson RN, MA, MSc1.2 O Amy Taylor PhD, MSc, BSc (Hons), PGCe, FHEA2.3 O Ed Richardson BA | Beatrice Greenfield MA, BSc. Bed Georgina Jones BA (Hons), MA, D.Phil, C. Psychol, Professor¹

Background: In 2020, the long-listing effects of the Covid-19 whos were not included in public messages of risks to public health. Long Covid emerged as a new and enigmatic liness with a serious and life-changing impact. Long Covid is poorly Check Toront of Made at Inciding, G & Foster, Easter, GK explained by objective medical tests, leading to widespread disbelief and stipma clated with the condition. The aim of this organic research is to explore the better EN MA Mir. Londo Bachett physical and epistemic challenges of living with Long Covid. Methods: Unlike any previous pandemic in history, online Covid communities and citizen science' have played a leading mite in advancing our understanding of Long Funding internation Shuffleic Hospitels Charlos Covid. As patient-lod research of this prassroots Covid community, a team approach to theratic analysis was undertaken of A6 patient stories submitted online to covid19-recovery.org at the beginning of the Covid-19 pandemic between April and September 2020. Results: The overriding theme of the analysis highlights the complexities and challenges of living with Long Covid. Our distinct themes were identified; the life-changing impact of the condition, the importance of validation and how, for many,

ORIGINAL ARTICLE

seeking alternatives was felt to be their only option. lasions: Long Covid does not easily fit into the stominant evidence-base practice and the biomedical model of health, which rely on objective indicators of the disease process. Padent testimonies are vital to understanding and treating Long Covid, yet patients are frequently disbelieved, and their testimonies are not taken seriously leading to stigma and epistemic injustice, which introduces a tack of trust into the therapeutic relationship. Patient Contribution: The research was undertaken in partnership with our

samer representative(s) and all findings and subsequent recommendations have been coproduced.

ORIGINAL RESEARCH PAPER

laspow, Glaspow, UK

Covertry, UK

.

'Reluctant pioneer': A gualitative study of doctors' experiences as patients with long COVID

Anna K. Taylor¹ | Tom Kingstone^{2,3} | Tracy A. Briggs⁴ Catherine A. O'Donnell⁵ Carolyn A. Chew-Graham^{2,3}

School of Matchine, Eventy Indication on Health Sciences, Faculty of Modeline and Health, University of Lends, Lends, UK School of Mindows, Rack University, and Health Sciences, Rack University, Rode, UK ¹Rosewith and Inservation Department, B Abstract Background: The coronavirus disease (COVID-19) pundemic has had far-reaching effects upon lives, healthcare systems and society. Some who had an apparently in COVID-19 infection continue to suffer from persistent symptoms, including chest pain, breathlessness, fatigue, cognitive impairment, paraesthesia, muscle and joint Horas's Hospital, Midlands Partners Bits Foundation Trust, Stafford, UK pains. This has been labelled 'long COVID'. This paper reports the experiences of In Procession From, Starting, Or. Initiation all Evolution and Genomic errors, School of Biological Sciences, archester University, Manchester, UK doctors with long COVID. Methods: A qualitative study: interviews with doctors experiencing persistent symp em were conducted by telephone or video call, laterviews were transcribed as analysis conducted value an inductive and thematic approach Results: Thirteen doctors participated. The following themes are reported: mak-"List of Academic Permane Care 1 ing sense of symptoms, feeling let down, using medical knowledge and corner Medical School, University of Warweld inny wanting to help and he beined combining outlant and modectional identity Carrespondence Anna K. Tartist University of Lewis, La Institute of Health Sciences, School of Medicine, Lewis, UK Dreal annuitednetficienties org uk operiencing long COVID can be transformative: many expressed hope that good old come of their experiences. Distress related to feelings of being 'let down' and the hard work of trying to access care. Participants highlighted that they felt better able to care for, and impathiae with, patients with chronic conditions, particularly No funding use declared for this study Conclusions: The study adds to the literature on the experiences of doctors as pa tients, in particular where evidence is emerging and the patient has to take the lead in finding solutions to their problems and accessing their own care. Patient and Public contribution: The study was developed with experts by experi ence Encluding co-authors HA and TAB) who contributed to the protocol and ethics application, and commented on analysis and implications. All participants were give the opportunity to comment on findings.

*ETWORDS dwork disease. COVID-19. doctors as patients, general practice, help-seeking, long COVID.

Original researc BMJ Open 'I can't cope with multiple inputs': a

qualitative study of the lived experience of 'brain fog' after COVID-19

Caltriona Callan,¹ Emma Ladds [©],¹ Laiba Husain,¹ Kyle Pattinson,² Trista Greentados [©]¹

To other Callian C, Ladda E, Hussain L, et al. 1 con 1 cop ABSTRACT Objective To explore the load experience of 'tran log'---Strengths and limitations of study a wide variety of neurocognitive symptoms that can To the best of nor knowledge, this is the largest must is depth qualitative study of the fixed exp ence of brain fog in survivers of COVID-13.
The research team was interdisciplinary and in reductional and included rand data with team utilities state of the weign and setting AUK-wide longitudinal qualitative study comprising online focus groups with ensul follow-up. Method: 50 participants were recruited from a previous qualitative study of the lived experience of long COVID-19 (n=23) and online support groups for people with pensistent nearecognities expertants following COVID-19 222,12:e056360, dai 1 njopen-2021-256366 presenter reactiongenese symptoms reacting control to (tr=27). Its remotely held focus propos, participants were invited to describe their neurocopytive symptoms and comment on others' accounts. Individuals were followed De journal addre (Mg.21da.d) org/13.1136/brigspan-3021-0563563 connects in other: accounts behavior and subject to be read = 4-5 motioned to be read = 4-5 motioned, therearchest, anonymael and code to MMO. They sees the subject by the information of the subject by th Received 11 August 2021 Accepted 28 January 2022 a UK sample suggest 1 in 10 people self-repo orground, otherwise unseptained symptoms 17 weeks after infection.¹ Over half experience a reduced functionality for everyday activitie and many remain unable to work weeks after erm train log', not descriptions of the experien cognitive symptoms (aspecially associative raction, attention, memory and languages, eczn icer the illness fluctuated — and progressed over time the protocoid psychosocial impact of the condition on infection.¹ The growing frequency of a and/or disabling illness related to COVID-I elationships, personal and professional identity; self enceptions of guilt, shares and stigma, strategies up has rendered their health needs, and and iated clinical and occupational guideline processing a pair, terms and input, processing and explaining the hadrower explane, and participant associate physical mechanisms is explain their symptome. Conclusion: These qualitative findings complement conclusion: These qualitative findings complement execution to the splaining and mechanisms of memory that symptomes after COV-18 Services. Its such patients should include an organing therapodic policy priorities.³⁻³ Long COVID-19, a 'patient-made' term.³ embraces the formally defined origoing symptomatic COVID-19 symptome (symp-toms persisting between 4 seeks and 12 weeks) and poseCOVID-19 undrome (symp-toms beyond 12 weeks).² In this paper, we use 'long COVID-19' to refer to the fixed patients Check for updates O Author(1) by their relationship with a clinician who engages with their periorice of musicogridive symptoms in its pa distant in RMJ incial and occupational context as well as specialist envices that include provision for neurocognitive experience and 'post-COVID-19 syndrome to refer to the medically diagnosed condi-Multistic Department of Print of Detect, Deberd, DK imptome, are accossible, easily nevigable tion. It is highly beterogenrous with sufferers reporting a range of fluctuating comprehensive and interdisciplinare.



uces the formally defined oppoint

WILEY

peniiting beyond 3 weeks, coining the expression 'long Covid' to cover them all. Clinical recognition came somewhat later (Greenhalsh et al., and and Perego (2000) call long Covid a "patient-made illness", the first to emerge by patients finding one another through social media. They describe how, in the aborace of bicanedical knowledge or medical legitimacy, online communities of Covid-19 'long haulers' exchanged

Patient-Led Research Collaborative: embedding patients in the Long COVID narrative

Lisa McCorkell^a, Gina S. Assaf^a, Hannah E. Davis^a, Hannah Wei^a, Athena Akrami^{a,b,*}

Abstract

A large subset of patients with coronavirus disease 2019 (COVID-19) are experiencing symptoms well beyond the claimed 2-week recovery period for mild cases. These long-term sequelae have come to be known as Long COVID. Originating out of a dedicated online support group, a team of patients formed the Patient-Led Research Collaborative and conducted the first research on Long COVID experience and symptoms. This article discusses the history and value of patient-centric and patient-led research; the formation of Patient-Led Research Collaborative as well as key findings to date; and calls for the following: the acknowledgement of Long COVID as an illness, an accurate estimate of the prevalence of Long COVID, publicly available basic symptom management, care, and research to not be limited to those with positive polymerase chain reaction and antibody tests, and aggressive research and investigation into the pathophysiology of symptoms.

Keywords: Long COVID, COVID-19, Patient-led research, Patient-centric, Long haulers, Post-acute sequelae of SARS-CoV-2 infection, Post COVID-19 syndrome, Patient-centered

PATIENT-LED RESEARCH COLLABORATIVE

OME RESEARCH ~ TEAM ~ RESOURCES ~ CONTACT US SITE MAP

About

The Patient-Led Research Collaborative is a group of Long Covid patients who are also researchers. We were born out of the <u>Body Politic Slack support group</u> and did the first research on Long Covid in April 2020. We are all researchers in relevant fields – biomedical research, participatory research, neuroscience, cognitive science, public policy, machine learning, human-centered design, health activism – in addition to having intimate knowledge of COVID-19.

About the Patient-Led Research Collaborative

"There's a lot of relapses involved... which, initially, was very, very demoralising, because [...] I would think, I've turned a corner, I'm going to get better, and then it would just suddenly get, like take two steps forward and three or four steps back."

(Burton et al., 2022; p5)

Disruption to daily life

Uncertain illness trajectory and prognosis

Sense of abandonment by health services

Stigma and discrimination

impact on sense of self and identity

"The past 7 months have been so devastating to both myself and my family [...] no one believed that Covid symptoms could last that long [...] I've had to argue with GP's to refer me to specialists. Covid clinics are not readily accessible to sufferers and, certainly in my experience, long Covid is not something that all GP's are happy to acknowledge."

(Ireson et al., 2022; p7)

"I still don't fully understand the balance between what might be a trigger [...] I'm terrified of an avalanche of chronic fatigue, like I'm standing on the edge of a cliff with no control over when and if I will fall" (Ireson et al., 2022; p9)

"Nobody is listening. I feel debilitated and so depressed."

"When patients were not listened to, it created a plethora of **missed learning and service delivery opportunities for the healthcare profession**. It also had a **significant impact on the care received** by the participants. By not listening or hearing their concerns, **the healthcare system left them vulnerable** to both the physical and mental impact of the virus, the emotional impact of being left to cope alone and the psychological impact of not being taken seriously."

(Ireson et al., 2022; p7)



HOW MIGHT WE MOVE...

FROM...

A health and social system which contributes to and exacerbates the psychosocial trauma experienced by people living with long Covid

то...

A health and social system which listens to and values lived experience and which bolsters psychosocial resources for navigating life in the context of long Covid



A starting point might be to...





Co-design clear flexible, and accessible pathways of care for long Covid



Treat every encounter with the health system as inherently psychosocial



Pay explicit attention to psychosocial experience and outcome



Practice humility and 'intellectual candour'



Remain emotionally aware and reflexive

In summary

lived experience of

Co-design clear flexible, and accessible

- Navigating life in the context of long Covid is as an inherently psychosocial process which has a profound impact on peoples lives
- Interactions with health services have so far exacerbated peoples trauma
- We need to get to know, understand and value
 - The unique and specific experience of individuals
 - The collective experience of the long Covid community
- An opportunity to design for positive psychosocial experiences and outcomes from the outset

candour

outcome



AUT CENTRE FOR PERSON CENTRED RESEARCH





Always in conversation . Engaging with diversity . Connecting as people . Pushing the boundaries