ADAMS, N.N., MACIVER, E., KENNEDY, C., DOUGLAS, F., SKÅTUN, D., HERNANDEZ SANTIAGO, V., TORRANCE, N. and GRANT, A. 2023. *Towards resilience: examining complex and hybridised coping strategies used by NHS workers experiencing long COVID illness*. Presented at the 2023 Annual conference of the British Sociological Association Medical Sociology Study Group (BSA MedSoc 2023), 13-15 September 2023, Brighton, UK.

Towards resilience: examining complex and hybridised coping strategies used by NHS workers experiencing long COVID illness.

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2023

ROBERT GORDON UNIVERSITY ABERDEEN

BSA Medical Sociology Conference 2023
Conference Stream: Experiences of Health and Illness

Towards resilience: examining complex and hybridised coping strategies used by NHS workers experiencing Long COVID illness

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*** Joint principle investigators**

LOCH
Long Covid in Health Workers

SCHOOL OF NURSING, MIDWIFERY AND PARAMEDIC PRACTICE

CHIEF SCIENTIST OFFICE

ROBERT GORDON UNIVERSITY ABERDEEN

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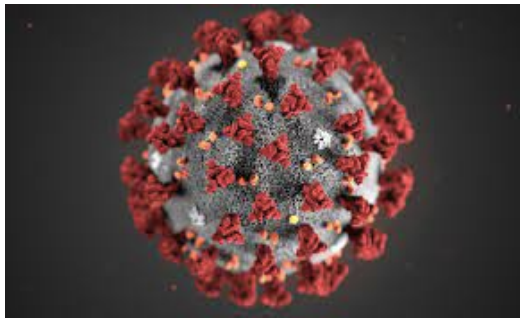
University of St Andrews

Background: *The LoCH Study*

Aims and Objectives:

- Long COVID (LC) effects 1.2 million people in the UK, including 120,000 NHS workers.
- LC remains poorly understood, comprising manifold symptoms ranging in severity, disrupting quality of life and work abilities: *Harrowing, life-changing, devastating, mourning a 'former life' and 'former self'.*



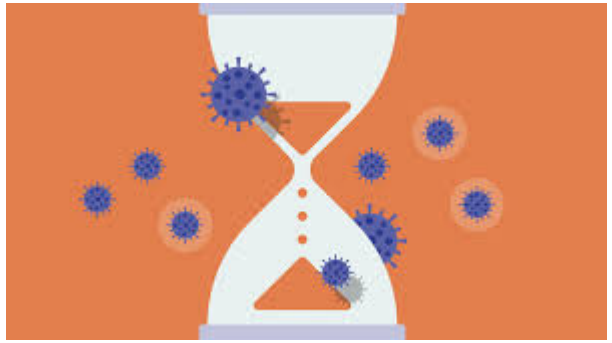
LoCH

Long Covid in Health Workers

Methods: LoCH - *A Longitudinal, Mixed-Methods Approach*

Methods Timeline: Quantitative

- Online questionnaire at two time points: Six months apart. Initial Q June 2021 – Oct 2021, Follow-up Q Feb 2022 – June 2022.
- Shared via social media, email advertisement from NHS boards circulated by internal NHS communications teams. Range of roles and occupations.
- Eligibility - Employed in an NHS healthcare setting in Scotland, 18+, self-identified as having prolonged Covid-related symptoms; including both ongoing C19 symptoms (from four to twelve weeks) and post-C19 LC (twelve weeks or more) (NHS, 2023). Positive C19 test not required.
- Questions: Long COVID symptoms, health and experiences around working in the NHS, HRQL (SF-12), EQ-5D-5L EQ-VAS, PHQ4, Promis SF-V1-4A.
- Q1 (n=471 completions) Q2 (n=302 completions). 11 NHS-S health boards.



Methods: LoCH - *A Longitudinal, Mixed-Methods Approach*

Methods Timeline: Qualitative

- Purposefully sampled at two time points: 1: September 2021 and January 2022, 2: March 2022 – June 2022.
- Semi-structured with interview guide, in-depth, online-based
- First interviews n=50
- Second Interviews n=44
- Over a hour, harrowing, participant wellbeing. Focus on being believed, barriers to healthcare access and treatment….but also…***resilience***
- Qualitative Analysis – Braun and Clarke, Mixed - Inductive, Deductive. NVivo used as an analysis aid.
- **Focus on these interviews for this remainder of this presentation.**

Resilience: 'Sociolog-ising' a Psychological Concept:

- Many definitions:
- Psychological Definition:

Resilience is the process and outcome of successfully adapting to difficult or challenging life experiences, especially through mental, emotional, and behavioral flexibility and adjustment to external and internal demands.

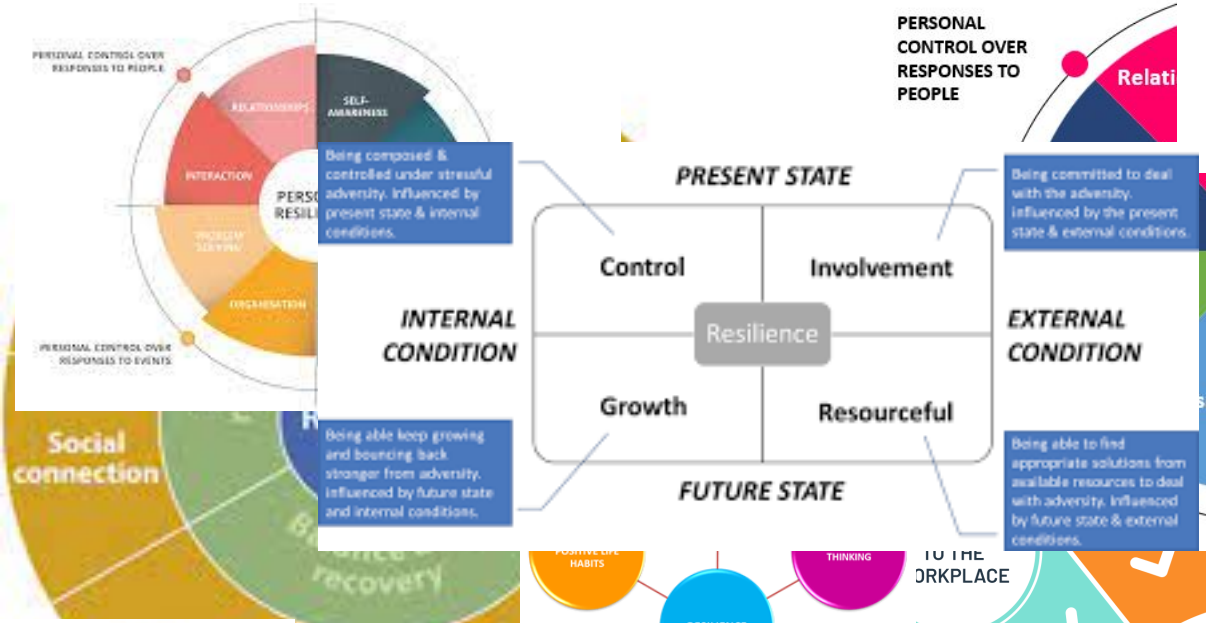
- American Psychological Association (APA, 2023)

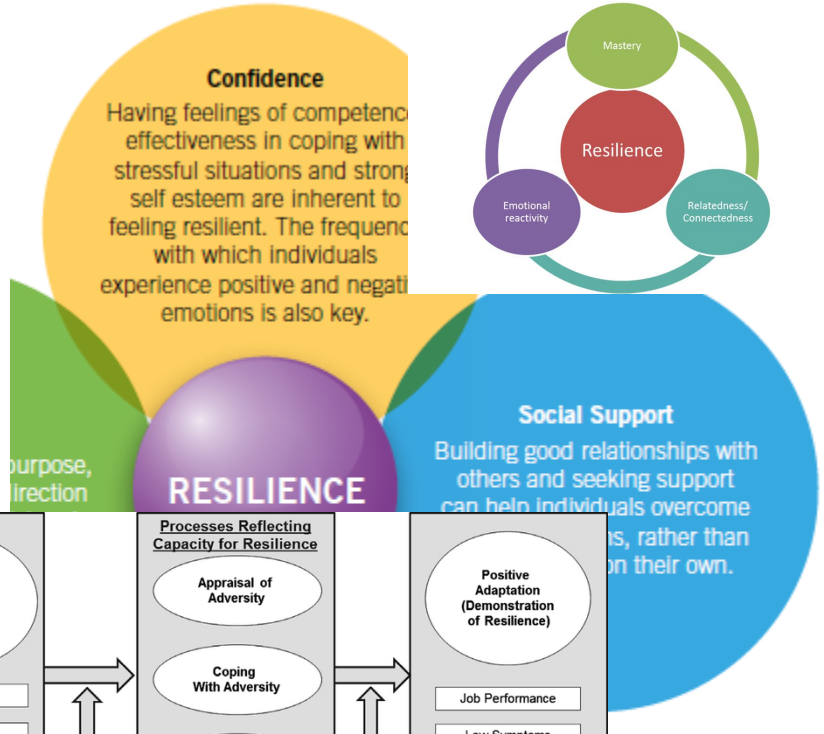
Resilience Theory: it is lesser the nature of adversity faced that is important, but how we deal with it.

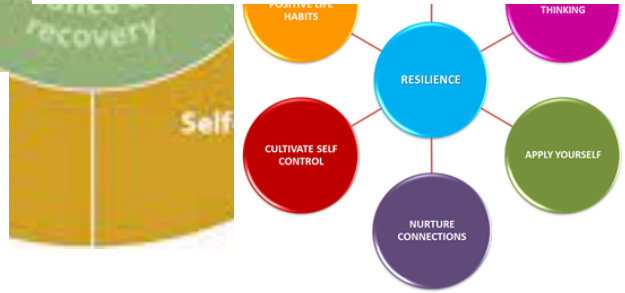
- Southwick et al., (2014), Yates et al., (2004).

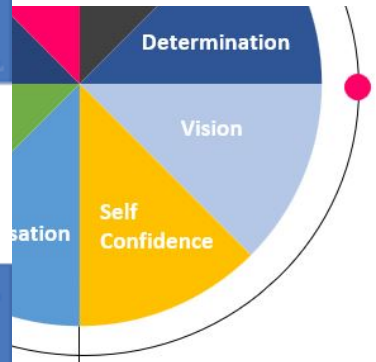
Resilience: 'Sociolog-ising' a Psychological Concept:

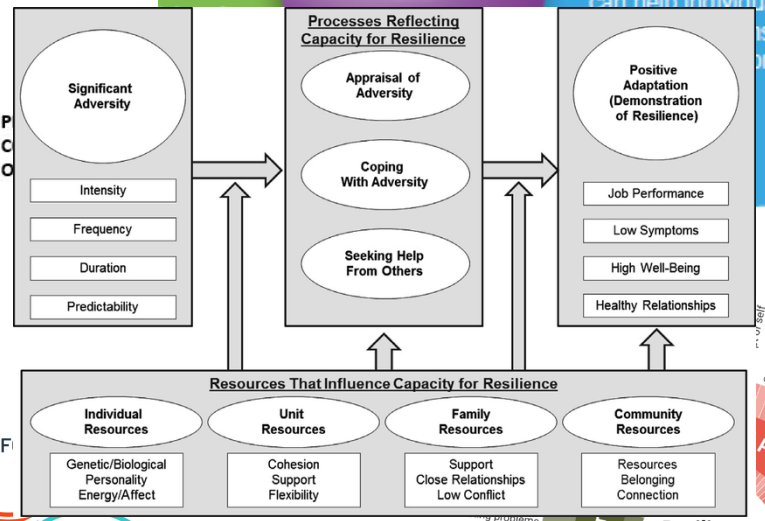
LOTS…of psychological-based models for resilience:

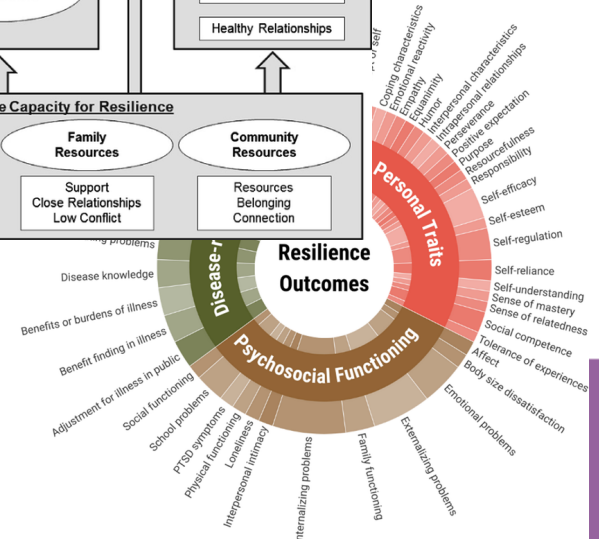












Resilience: a Psychological Concept:

Psychological Definitions…some considerations -or 'gaps'- when applying Resilience Theory outwith clinical contexts:

- Troy et al., (2023)
- Anasori et al., (2023)
- Altinay et al., (2023)
- Killgore et al., (2020)
- Vella & Pai (2019)
- Fletcher & Sarkar, (2013)

- Prescriptive: Adversity = distress = psychological dysfunction
- Overall focus on 'fostering and building resilience' as opposed to understanding or acknowledging that some levels of resilience are developed 'naturally' via 'self-interventions' rather than 'taught initiatives'.
- Focus on **'returning to baseline… / homeostasis'**
- Theories largely ignore the influence of individual identity upon resilience, how identity shapes perceptions (siloed approach, no joined-up thinking).
- Focus on the 'rational' (anchoring) and 'emotive' (control) over micro-level personal understandings of what resilience may mean to different social actors.
- Largely, downplay importance of available resources and how they can be used, adding and detracting from resilience capacity (i.e. cognitive load, mental models, macro-local sense-making). (Assumption all starting from a similar 'low resilience' baseline).
- Overly 'medicalized' – 'psychologica-sized?'

Resilience: 'Sociolog-ising' a Psychological Concept:

Constructing a **Sociological Definition**:

- Matin et al., (2018)
- Endress (2015)
- Stark, (2014)

- Adaptive
- Sociological Resilience literature sparse.
- Is developing resilience 'costly' (psychology) or upgraded with use (sociology)? (Stark, 2014).
- Resilience is not a set process to 'develop' when facing adversity, *being human* naturally develops resilience skills which can be applied to new challenges and adversities (Martin et al., 2018; Stark, 2014).
- 'Resilience' should be framed as an interpretive; individual and *personal* term, as opposed to a 'catch-all' clinically-focused definition (Martin et al., 2018).
- 'Resilience' is fluid; socially-constructed from other life experience, contextual and presenting factors – a collection of internal and external resources (Endress, 2015; Martin et al., 2018).

Illness Trajectory Theory

- Corbin and Stauss (1985), Updated, 1991, 1998)

Managing Chronic Illness at Home: Three Lines of Work

Juliet Corbin and Anselm Strauss
University of California, San Francisco

ABSTRACT: Problems of managing chronic illness at home are addressed in terms of the concept of "work:" what types and subtypes of work, entailing what tasks, who does them, how, where, the consequences, the problems involved. Three types of work and consequences of their interplay are discussed: illness work, everyday life work, and biographical work. Theoretical concerns of the sociology of work are addressed as well as the substantive issues of managing chronic illness.

Core theory components:

- *Identifies problems managing chronic illness at 'home'*
- *Highlights the concepts of 'work' or 'effort' involved in management.*
- *Three key domains*
  - ***Illness Work***
  - ***Everyday Work***
  - ***Biographical Work***
- *Focus on 'interplay' between the domains*
- *-Highlights- How 'illness trajectory' and it's components and coping 'interferes' with 'normal life'.*

Framing Long COVID in terms of 'illness trajectory' (Corbin and Stauss, 1985, 1991, 1998).

- Definition of Resilience – what can we contribute to resilience by examining the narratives of NHS workers experiencing Long Covid Illness?

- How can our understandings of resilience development be used to suggest workplace supports for the NHS.

- New Illness, complex and challenging to diagnose, unique 'symptom' experience and journeys for each individual…but also…lots of overlap and points of commonality with regards to challenges faced.
- (Largely) an absence of literature exploring resilience
- Most literatures and findings re Long Covid (including ours) highlight LC experience as negative; disruptive to work, life and identity.

- **Three key themes I want to focus on:**
  - Reframing
  - Self-therapy
  - Preparation

  ——— • Interlined *Illness Work* and *Emotional Work* = *Everyday Work*

Findings: *Towards resilience: examining complex and hybridised coping strategies used by NHS workers experiencing Long COVID illness*

1. Evidence of *A journey of Reframing* - Illness and Capabilities

Key problem statements:

- *Denial - I'm 'fine' I have to 'keep pushing', maybe I don't have Long COVID, I need to 'get in with it'*

Active solutions constructed:

- *Resource Calculating: Self-awareness and the importance of rest (framed not a healing/recovery function, but a processing function; giving individuals the time to think about and come to terms with their new limitations and cognitively process the impacts of these.*
- *Pacing and 'small steps' – rebuilding goals*
- *What positives can be taken from Long COVID: enhanced empathy, better understanding of patients, better understanding of the medical system and biomedical model of diagnosis and it's limitations. New applications for clinical role.*

What I found with long COVID was, when you push through, you suffer for it […] I've never had a situation like that before. I've been ill in the past where you have a bad cold or a bad chest infection, and you go to work because you just, you've just learned to push through, you don't go off sick unless you're in hospital. […] with long COVID it does the opposite. You push yourself and then you just crush and you become more ill, and you get up and you push yourself again, and then you just fall even harder. So, I find that really hard.

- Doctor (Primary Care, GP) Interview 1. (Participant 11)

It is just pointless to just go out for 10 minutes or, shall I go for a walk around for 10. I'm thinking, what is the point of leaving the house and walking about 10 minutes. And the only time I did try and after 10, 15 minutes, I had to come back home and I was so discouraged cause I just thought, what's the, and like I was tired and I got on my bicycle and I just came off, I fell off my bicycle whilst riding and it was because I was trying to push.

- Doctor (Primary Care, GP) Interview 1. (Participant 11)

I'm now able to […] do things, you know, […] sometimes it's a bit like self-preservation. So sometimes, I won't go up the stairs until I have to or, you know, - so some things I actually consciously do to preserve [energy], it's like having ***that bucket of energy and knowing that this is how far it will go****. And so, therefore, saving it for some things and not using it up on some other things. […] Those kinds of things I will sometimes do now because I'm conscious of the effects it then has on me . […] So, there is some improvement. Yeah, there has been an improvement, it's just, there still a lot that's not right and I haven't improved enough to do some of the things I would have expected. Like being able to do my four, my quota. It's not as bad, but it's not disappeared.*

- Same Doctor (Primary Care, GP) Interview 2. (Participant 11)

2. *'Self-therapy' Linked Cognitive and Psychosocial Restructuring*: (C-P-R): Anchoring and Reasoning - Work, Role-Identity - Sense of Self, Sense of Purpose.

Key problem statements:

- *I've lost my identity – I'm no longer fit and healthy, I can't work like I used to. I was previously 'high functioning', now, I'm not. (Doctors in particular).*

Active solutions constructed:

- *Realisation: I have to develop my own solutions to progress positively and move away from the 'stagnation phase' of Long COVID illness.*
- *Honest reappraisal and reevaluation of 'wellbeing' and 'health' and 'capability' status.*
- *Re-attachment to work, social life, exercise and engaging in life.*
- *Re-assessment of identity, a 'letting go' of a former self, and a new beginning -a reconstruction- of self moving forward.*

I've been to two support groups. One of them is a general ICU recovery group and the other one was a more specific COVID recovery group. The general ICU recovery group, I was conscious, looking at myself at amongst the rest of group, I [felt that I] got away pretty lightly […] compared to some of the other people that were there.
And my wife, she came along to that meeting and commented afterwards that there was definitely a glass half full scenario in some of the people in the group, and glass half full, empty, a glass half empty scenarios from some of the other people in that group.
I said to her, well, we need to make sure that we don't become a glass half empty person, that's, that's for sure.

- Medic, Specialist Doctor, Secondary Care. Interview 2 (Participant 30)

3. Preparing for and dealing with setbacks and negotiating continued personal Growth: participant's developing and utilising their own (and others') knowledge and experience to mitigate ongoing uncertainties:

Key problem statements:

- *Uncertainty: I don't know what the future holds… how will I cope?*
- *What will happen if I get Covid again, get worse following a booster, re-lapse from 'pushing myself' or become more unwell for an unknown reason.*
- *Social Media: Other people are recovering 'faster' and 'better': why am I different?*

Active solutions constructed:

- *If 'the worst' should happen: I have recovered a little - I can recover more.*
- *I am learning more about myself, my body and mind, and my illness experience every day, I am an expert in my own illness experience.*
- *Social Media: By interview 2 – a majority withdrawal from social media, where engagement was previously high (all groups).*
- *Renewed networks of 'real world' friendship – what matters is 'in the moment'. Not taking health for granted, a renewed health focus.*

I went to a concert three weeks ago with friends, and I think that [made] a difference. Like if you're with other people who know you, and know what's been going on. And yeah, most of my friends are, yeah, cautious. Some of them work in health as well. So, yeah, going to the concert was a bit of a big thing, cause it was a big concert. Most people didn't have masks, but I realized that yeah, I've I've got techniques now that I work through if I start feeling, you know, anxious, and I think it's been hard letting go and kind of saying, well, it's people's decisions, you know, what they want to do or not do. And I'm just gonna do my thing, sort of thing. I don't often choose to go into places where there, you know, many people I have to be honest. I haven't travelled, yeah, too far from, yeah, the surrounding areas of [where I live] I wouldn't say. I've got friends in London and I've been putting that off, just because they're going quicker than we are in terms of, yeah. But I know friends who have gone and, they've been okay, you know, like psychologically and even people who are even more cautious than I am. So yeah, just slowly, I think through other people's experiences, just being with other people at the time when I'm going to places. Yeah, I think this job is really helping me because, yeah, we're in close proximity, you know, with patients, and as I said, you know, sometimes they don't wear a mask.

- AHP; Allied Health Professional; Occupational Therapist. Interview 2. (Participant 27)

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Summary and Conclusion: Towards a *psychosocial* framework of resilience for NHS Workers learning to cope with Long COVID illness

What we didn't find…

- No 'structured' or 'learned' formal framework for resilience. It was not a prescriptive process.
- Individuals did not 'return to baseline / homeostasis' nor did they focus on this as a positive component of recovery, in opposite, when individuals focused on 'who they previously were' or 'recovering their previous self' this impeded their functional recovery and development of resilience, they became stuck in uncertainty, despair and denial.
- Emotional control and regulation was minimal, participants instead embraced emotions and emotional expression as part of the resilience journey i.e. "grieving their former selves".

What we did find…

- Resilience developed slowly, following a period of uncertainty, disruption and denial about new limitations and changes.
- Resilience developed holistically from a combination of different 'largely negative' experiences, which led to the construction of new 'positive' ways of thinking and adjusting to limitations.
- Resilience was independent from a functional recovery. Developing 'resilience' allowed individuals to prepare and cope better with new challenges and ongoing recovery issues, NOT to fully recover.
- Resilience did not occur in a vacuum. Developing resilience was highly personal and conceptual; constructed from different available resources (including financial, social capital, medical, personal understandings and cultural experiences and resources).

Summary and Conclusion: Towards a *psychosocial* framework of resilience for NHS Workers learning to cope with Long COVID illness

***Key learnings for structuring workplace supports*:**

1. Space and Time: Resilience takes time to develop and can be impacted by additional burdens; i.e. being 'encouraged' to return to work too early. Large part of developing resilience was down to individuals having the space and time to come to terms with and understand their Long COVID illness, become their own expert in order to develop sense-making and solutions that worked *for them*.

2. Role and Resource Allocation Flexibility: being as flexible as possible with work routines and workers unique management strategies for Long COVID illness. One size does not fit all, but all strategies involved linked Illness and Emotional work.

3. Believing individuals about their Long COVID illness and it's limitations: Illness and Emotional work is not visible to employers, but it is happening 'behind the scenes'.

Thanks, Questions:

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