DOCTORS FOR THE NHS
SERVICE NOT PROFIT
NEWSLETTER

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The Politics of Risk: Paying with People's Lives?

It is nearly 5 years since the tragedy of the Grenfell Tower inferno, in which 72 people lost their lives. Each week I listen in horror and in anger to the account of the ongoing judicial inquiry into the disaster, captured in the BBC's Grenfell Tower Inquiry podcast (1).

A narrative of incompetence, ignorance, complacency and greed has gradually unfolded through the able cross-examination of witnesses. An unhealthily cosy relationship between the construction industry, regulators and government is appearing, with strong suggestions that commercial interests have been a greater priority than public safety. A background of an ideologically driven bonfire of red tape has not only left us with badly designed modern developments of cramped homes that are costly to heat and poor settings in which to raise our children, but also fire regulations that ignored changes in building materials and construction techniques (2). Many people paid with their lives: very many more are living with the consequences of these failures. We owe them a duty to take risk more seriously.

The Inquiry will not publish its definitive report for some time yet, but many revelations already have resonance in other areas of public life, including the numerous attempts over the past 30 years or more, to open the NHS up to commercial interests. After all, private businesses are dashing entrepreneurs – risk takers! We are told that this is for the benefit of the NHS and the patients it serves. What rubbish! It is for the benefit of private businesses, greedily eyeing up the guaranteed mountain of public money that is the NHS budget. The risks are to the services the public depend upon.

Ignore political rhetoric: most doctors are not risk-averse. A large part of our job involves managing risk – acknowledging that our actions and inactions carry risks for our patients; assessing those risks; devising strategies that should produce the greatest benefit with the least risk; and helping our patients to understand the options before them so they can participate in the decisions that need to be taken.

Most NHS plans also contain a risk assessment, assessing the likelihood of particular adverse events occurring, the severity of the impact, should they occur, and the actions that can be taken to mitigate those risks. Risk assessments demonstrate that you have a Plan B, if things don't go as well as you hoped.

In contrast, the parliamentary procedures involved in agreeing the legislative framework within which the English NHS operates seems positively to discourage any acknowledgment of possible adverse outcomes as a result of proposed changes, despite cumulative evidence to the contrary stretching back many decades. The Treasury's *Orange Book*, which is supposed to ensure risk management is an integral part of the design of public services, doesn't seem to apply to the drafting of legislation (3). It would seem that we need to rely on scrutiny of draft legislation in the Committee stages of the passage of Bills for any risk assessment in a public forum.

Largely unscathed

The Health and Care Bill has completed its Committee and Report Stages in the House of Lords and 60 or more amendments have been incorporated into the Bill, ready for its Third Reading in the Lords on 23rd March at which point further amendments can be tabled. It will then pass back to the Commons for their consideration of Lords amendments, which may be accepted, or rejected. It will pass between the two chambers until agreement is reached.

There is no evidence of any political appetite to abandon the principle of integrating services by breaking up the English NHS into 42 distinct

Integrated Care Systems (ICSs). The proposed structure of each ICS is unchallenged, with Integrated Care Boards (ICBs) as statutory bodies, directly accountable for NHS spending and the performance of the system and Integrated Care Partnerships (ICPs), which are made up of a wider and loosely defined group of organisations, responsible for developing a strategy to address the health, social care and public health needs of the population covered by the ICS.

There was strong criticism of the extent to which Parliament was being side-lined in delegating power to ministers and NHS England, through Henry VIII clauses – clauses in a bill that enable ministers to amend or repeal provisions in an Act of Parliament using secondary legislation, usually subject to less parliamentary scrutiny. Henry VIII preferred to legislate by proclamation, rather than through Parliament. He appears to be alive and well. "Of the 156 delegated powers, more than half are subject to no parliamentary procedure."

The Constitution Committee of the Lords reflected a sense of frustration, verging on outrage: "The Health and Care Bill is a clear and disturbing illustration of how much disguised legislation a Bill can contain and offends against the democratic principles of parliamentary scrutiny."

Reports from Greater Manchester of a nurse with serious burns being denied care at two hospitals, because of her residing outside their catchment areas has raised concerns that the Bill might make it more difficult to receive emergency treatment when travelling outside their ICS area. (4) Amendments seeking to remove that risk were rejected by the Government because, "It would not be reasonable to expect providers to provide services regardless of whether they were funded by an ICB to do so, and it is important that ICBs should be able to make decisions about with whom they contract and where they prioritise their resources." They would seem to prefer that the risk should remain with the victim.

Attempts to move amendments to maintain national terms and conditions of employment, including agenda for change, were unsuccessful, presumably revealing deliberate intent to sideline such agreements.

How has the Bill changed?

A major concern has been that profit-seeking individuals or organisations could be appointed to ICBs or ICPs and influence the design of services to meet their preferred business model, rather than the needs of patients. The original draft of the Bill would have permitted this, with only vague and weak indications of how conflicts of interest might be managed (not avoided). Under pressure, the Government amended the Bill so that "The constitution (of the ICB) must prohibit a person from appointing someone as a member … if they consider that the appointment could reasonably be regarded as undermining the independence of the health service because of the candidate's involvement with the private healthcare sector or otherwise."

However, much of the commissioning of services would be delegated to place-based committees and subcommittees. Recognising this loophole, an amendment was passed by their Lordships to "avoid the appointment of anyone who would be perceived to have a conflict or potential conflict of interest" to such committees (5). The Bill still permits many routes by which the influence of commercial organisations might be brought to bear – but we would be fooling ourselves if we believed that this does not already occur, including through lobbyists and the activities of the big accountancy and business management firms (6). Of course, this amendment, and others, might well be rejected by the House of Commons, if they felt the resulting delay to the Bill's passage would be manageable.

The original Bill did nothing to address the scandalous absence of a funded workforce plan for health and social care – our largest public services. An amendment that goes part of the way was eventually agreed. "The Secretary of State must, at least once every 2 years, lay a report before Parliament describing the system in place

for assessing and meeting the workforce needs of the health, social care and public health services in England… an independently verified assessment of health, social care and public health workforce numbers, current at the time of publication, and the projected workforce supply for the following 5, 10 and 20 years; and an independently verified assessment of future health, social care and public health workforce numbers based on the projected health and care needs of the population for the following 5, 10 and 20 years." (7)

There are serious concerns that the Bill could make it more likely that patients could be discharged from hospital to their homes or other community settings prematurely, without adequate provision for their ongoing care, or without due consideration of informal carers, through the 'Discharge to Assess' process. An amendment reflecting some of those concerns was agreed: "Carers and safe discharge from hospital" [retains the principle and duty on a hospital, whether it be an NHS hospital or independent, to ensure that a patient must be safe to discharge from hospital and mirrors carers' rights which were established in the Community Care (Delayed Discharges, etc) Act 2003.].

Other Lords amendments agreed included mandating a member of each ICB to have expertise in their local mental health service; maintaining the existing safe haven for patient data across health and social care; consultation on a statutory scheme for regulation of prices and profits of the tobacco industry, with funds raised to pay for tobacco control measures (8); and a mechanism for resolving disputes between parents and clinician in cases of palliative care in children (9).

There has been some detailed scrutiny of the Bill in the Lords and worthwhile amendments, but in my view it remains a deeply flawed piece of draft legislation, posing serious risks to the public, while failing to address the main threats to our NHS.

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Medical Aid Ukraine

Dr Vladyslav Vovk (picture) is a trainee (F2) doctor at North Tees NHS Trust. He came from the Ukraine with his parents when he was aged 9, and lives and studies in the North-East. He is one of the organisers of the North-East region for Medical Aid Ukraine, which has gained wide NHS and public support in organising the shipment of medical supplies and equipment:

'I still have lots of friends and family back there, in the conflict. My decision to get involved was personal. This has been the biggest conflict there has been in Europe since the Second World War so part of why I did this is wanting to make a real difference to the people who are most affected by it. Part of it is my own personal motivations with having family there – quite frankly I don't know whether I will wake up tomorrow and they will still be alive and that's quite shocking to say. But it's true.

'I've two cousins, one fled to Germany, one was a trainee doctor in Kyiv when the war started in one of the largest children's hospitals, looking after paediatric oncology patients there. She's sent pictures of children in corridors and lying on mattresses on the floor, some of them nursed in basements. We're trying to get the one who fled to Germany here but the process is quite tedious, they want official translations of every single document that we've got and that's tough.

'I absolutely thought this would not happen in Ukraine. We watched the military vehicles amass next to the border for a few months, and it was on the news for a bit before it happened, but everyone was convinced it wasn't going to happen. Almost overnight everything changed, it was just unexpected. I'm extremely angry to be honest. I think in the first few days I wanted to go out there and I wanted to fight but my Dad sat me down and said I could use my skills in a more constructive manner, hence why I got involved with Medical Aid Ukraine (MAU).

'We're a dedicated group of volunteers, most of us medics, who all have deeply passionate reasons for getting involved. The idea started in the North-East but quickly took off over the whole of the UK. We're trying to get as much medical aid to Ukraine as possible, mainly as life-saving equipment at the moment, torniquets etc; everything else comes later once the acute issues are sorted.

'In 2 weeks, MAU has gone from zero to 120 miles an hour without a doubt! In the past couple of weeks we've sent off about three and a half thousand kilos worth of medical supplies. There's been four ambulances from the North-East alone, five more from London. So it's a pretty big operation and it's only just getting started really. We've got logistics going from air, from land, we're working on sea logistics at the moment. The bottleneck we've got is to try and get the supplies from the Polish warehouse over into Ukraine so we're working on different routes that we might be able to establish to get stuff into Ukraine. How on earth can you drive an ambulance across a national border when missiles and shells don't respect ambulance neutrality? Putin demonstrated his willingness to strike anywhere within Ukraine's borders and at humanitarian aid. We're working with the official channels but they're being overrun with the amount of stuff they need to move. But we don't want the equipment to sit there in a warehouse.

'I'm getting almost daily messages of aid that people are wanting to donate and send – I've even had people contact me to say they're willing to drive stuff over there even though it isn't safe – and I'm so grateful and overwhelmed by it all. I think the whole of the healthcare sector has come together in a way which personally I've never really witnessed before. Ironically, that's been the most wonderful experience.

'Historically Ukraine's healthcare system was meant to be government funded on the polyclinic model where you went to see a GP then got referred the same day, you saw a specialist, just going from one queue to the next. In practice this worked ok but it wouldn't work that well on a large population simply because the waiting times

would get out of hand. Doctors are horrendously under-paid, earning the equivalent of a healthcare assistant wage. When my parents were in Ukraine in the 1990s they were being paid with rice sometimes, the economy went to pot after the Soviet Union broke down. There were patients in queues with chickens. So there was not a great deal of resilience in the system to start with, before the war started.

'With the infrastructure such as it was all but gone at the moment, there are public-health and longer term concerns. My Grannie in Ukraine has severe osteoarthritis and was meant to be getting hip replacements but who knows when that is going to happen now? It's really tough for the people who have to get routine care, all that has ground to a halt. I think the long-term consequences will be fairly similar to the chronic fallout that Covid has wreaked on our hospitals in the UK, affecting longer term care; and that's without the infrastructure being affected as it so obviously has in Ukraine. That will take years to re-build.

But do you feel hope?

'I think there's a lot of hope. The war has dragged on for longer than anyone thought and Ukraine has continued to hold on. I think there's hope for a reasonable outcome even though unfortunately short term lives have been lost and we're trying to mitigate this. I think in the long term Ukraine will be better off for it, maybe after about 20 or so years.

'I think Putin is very much a Cold-War era man. He was made during that time and he still carries forward a lot of those same attitudes: it's Russia versus the West, it's NATO expansion. Which is ultimately Cold-War era thinking. I'm very glad that one way or another this will come to an end, because no matter what happens now I think he's demonstrated that he will not be President for very long after this.'

What can people do?

MAU North-East has its own site (https://bit.ly/MAUNE) and we have on there the list of equipment we need. People can also go on to the MAU fundraising site (https://bit.ly/MAUdonate) We also have a Twitter (https://twitter.com/MedicAidUkraine) feed. We're also working with the OnCall Room (https://twitter.com/TheOnCallRoomUK).

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Taking the Strain: Resilience in the NHS

Mark Tan (one of our Essay prize runners-up, see Page 13) works as a dual trainee in anaesthesia and intensive care medicine but is also an NIHR academic clinical fellow completing a Masters in global health with the Humanitarian and Conflict Response Institute (HCRI), University of Manchester. Here, he discusses his views on the NHS, resilience and health inequalities

The NHS and resilience

My current research focus is healthcare resilience, so this topic is very close to my heart, and head. Resilience is an over-used and poorly understood concept. Current understandings stem from research traditions including psychology, engineering, socio-ecological systems, aviation and patient safety, to name a few. Within healthcare, resilience may be considered on various levels; micro- (individual), meso- (organisation) and macro-level (national and health systems). Clearly, there are issues with this hierarchy. For example, team resilience is not accounted for, nor is the boundary between a single health facility and its interfaces with other regional bodies. Both lie in-between the prescribed levels, but are important factors for success. Moreover, the ongoing Covid-19 pandemic and the climate crisis demonstrates the need for international cooperation and collaboration. Yet, this "meta-level" is not a key feature of the academic literature yet.

On an organisational and systems level, a classical definition is the ability to anticipate, respond, monitor and learn from a shock or crisis [1]. Based on this, we could evaluate how resilient the NHS actually is. Overall, the NHS anticipates and prepares for many events. This is demonstrated by our well-structured and world-renowned trauma network. We have regional and national frameworks for major incidents, chemical events, natural disasters and other crises. Our research network has been an exemplar in the multiple international Covid-19 trials. There are even "sleeper trials" developed after the Ebola epidemic. These pre-approved trials aim to minimise the time needed between the onset of an epidemic, and the beginning of robust research. Now within the Covid-19 pandemic, there was not so much a lack of recognition of the importance of preparedness for emerging infectious diseases, but more of a lack of addressing previous calls to focus on such scenarios.

Is the NHS good at responding? I think the jury is out with regards to the Covid-19 pandemic. The knee-jerk reaction to the pandemic was an almost complete prohibition of social activities under the premise of infection control. However, we only retrospectively recognised the importance of social networks and human connection, particularly during times of critical illness. This was one of the focal points in my essay Critical but Stable (page 13, which I am glad to say will be published in revised form in *Intensive Care Medicine* very soon). Even more importantly is the wider recognition of death and dying as a relational and spiritual process, not just a physiological one. This underpins the recent Lancet Commission into the Value of Death [2].

Another point of divided opinion is the UK government's response to Covid-19. It is important to acknowledge that some decisions they have had to make were extremely difficult. Central to this is the intricate interplay between healthcare, economy, and public expectation. Good quality

healthcare is expensive, and medicine has generally evolved to involve more costs, not less. Yet, there is a deeper need to challenge the capitalistic and purely financial assumptions about a "strong economy". New Zealand's Living Standards Framework for example considers four capitals: physical/financial, human, natural/environmental, and social. In this way, they take baby steps away from a purely financial interpretation of capitalism. There will be many points of both criticism and praise for the UK government's actions. Perhaps the key is to possess the integrity to acknowledge both. In "resilience-speak", this fulfils both safety1 (learning from adverse events) and safety2 (learning from excellence) approaches.

Monitoring: well, the NHS is particularly good at monitoring. The popular poster placed in public toilets about how 20% of people do not wash their hands perhaps epitomises our obsession with monitoring. But more seriously, think about A&E's 4-hour wait, bed occupancy rates, lengths of stay, mortality data and medical revalidation processes. Governance is a strong point of the NHS, and we should be proud of it. Granted, there are issues regarding pointlessly chasing metrics, or the punitive reductionism of surgeon-specific mortality data. But that we have robust governance structures which span from individual to national levels is something which underpins evidence-based medicine and self-improvement.

Finally, we explore learning and improvement. On an individual level, the fact that the word "resilience" has been thrown around (sometimes haphazardly) signifies our collective recognition of the importance of a robust workforce. That many doctors now roll their eyes at even the mention of it demonstrates there is far more to learn at higher levels. Fortunately, the NHS operational strategy for 2022-23 acknowledges this and seeks to expand opportunities for more flexible working [3]. Clearly, improvement is slowly occurring at a national or macro-level. But there is still very little written about how organisational (including hospitals) structures and policies can help to boost individual resilience. Such inter-level work is required to prevent just paying lip-service to a trendy term.

Another opportunity for learning is the use of telemedicine and video-technologies in medicine. Covid-19 dramatically accelerated its adoption within medicine. GPs have embraced it. ICUs mitigated some of the detrimental effects of visiting restrictions with it. Education and training programmes have increased their reach. We now need to examine how best to balance this with relational aspects, and financial considerations, which are equally important.

"Governance is a strong point of the NHS, and we should be proud of it...there are issues regarding pointlessly chasing metrics, or punitive reductionism of surgeon-specific mortality data."

Global health inequalities

There is no doubt that universal healthcare (UHC) helps to reduce health inequalities. But there is a need to examine three issues more deeply within this area: the definition of health, the history of global health agendas, and a realistic understanding of health economics.

The World Health Organisation's (WHO's) definition of health is widely accepted as a "state of complete physical, mental and social wellbeing" [4]. This is problematic for a variety of reasons. Not only does it fail to consider the less-than-complete-wellbeing experienced by many with chronic illnesses, it also inadvertently medicalises health. Fortunately, WHO also began recognising the importance of Social Determinants of Health

(SDH) [5] some 65 years later. Alternative definitions of health take a resilience lens and frames it within self-adaptation [6], but this has its own problems. Whatever our interpretation, it should be noted that only a small proportion of health is determined by formal healthcare, yet it receives up to 20% of a country's budget. Other social determinants of health include clean water and sanitation infrastructure, educational opportunities for all, employment and monetary means, national security and political stability, amongst others. Listed like that, most would acknowledge their importance to health. Yet, medical schools continue to use a pathology- or disease-based approach to educate doctors of the future.

This brings us to the history of global health agendas, which is intricately woven with the pursuance of universal healthcare. The Alma-ata agreement of 1978 formed the first international agreement for primary healthcare [7]. Further iterations and alternations included the Human Rights Approach to Health, the Millennium and Sustainable Development Goals, and more recently, the Triple Billion Targets. Yet more than 40 years after Alma-ata, many countries still lack universal healthcare provision [8]. Despite all of this, metrics of health continue to improve globally [9]. Much of this progress is due to said social determinants, rather than formal healthcare. Nevertheless, global health inequalities continue to disproportionately affect low-income countries, but universal healthcare can help to minimise the effects of such inequalities.

In case one begins to think of universal healthcare as a panacea, we then start to consider a health economics perspective. According to the classical supply/demand graph of economics, the provision of universal healthcare inevitably increases the demand and therefore the cost of healthcare. This in turn leads to the tendency for overtreatment. This unsustainable economic trajectory of unrestrained medicine, particularly in high-income countries, is a prominent undercurrent within the Lancet's Commission into the value of death [2]. The NHS

attempts to mitigate this through cost-effectiveness analyses, unlike our transatlantic colleagues in the USA. But during the Covid-19 pandemic, USA implemented Crisis Standards of Care [10], which the NHS was unwilling to formalise. Yet, there is widespread public recognition of the unspoken lowering of standards within the NHS, from the extended waiting lists for interventions to the late diagnoses of life-changing conditions. Clearly, health rationing is an issue which needs to be more widely and openly debated.

All of these must be taken into the local and global context again. Covid-19 exposed the dramatic health inequalities even within the UK, from excess mortality in Black, Asian and Minority Ethnic (BAME) populations to re-highlighting socio-economic factors leading to poorer resilience and resistance of individuals and communities. On a global scale, the unavailability of vaccines in Africa shone a spotlight not only to the lack of equity, but also held a mirror up to our own selfishness. The numerous variants and decrease of protection is a harrowing reality of a statement made by the Ethiopian prime minister early in the pandemic, "if Covid-19 is not beaten in Africa, it will return to haunt us all".

In the end, all is not doom and gloom. Here is an example from the natural world. In the 1990s, Varroa mite and the diseases they spread caused severe honeybee colony mortalities [11]. This has led to the predominant rhetoric about the potential extinction of bees in popular media. Yet, within a few years, wild colonies were observed to thrive

despite Varroa [12]. It is now understood that a multitude of factors conferred survival benefit against the mite. Global honeybee populations have since recovered, to the point that the density of human-managed honeybee colonies in some areas is now so high that it affects the populations of other pollinators.

Human history is similarly one of resilience. Despite two world wars and a potential third on the horizon, we have, and will continue to survive. Despite epidemics, pandemics, natural disasters and global health inequality, overall health metrics continue to improve. Despite the escalating climate crisis, we do possess the power and ability to change its trajectory. But to do so requires international cooperation and collaboration which is multi-disciplinary, cross-sectoral and inter-level. This is a vantage that takes a planetary rather than just a national, regional, local, or indeed individual view. In that sense, there is still wisdom in the Biblical phrase "…I must become less".

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The Peter Fisher Essay 2021: Runners-up

The next two runner-up entries for this year's Prize. We will be publishing further runners-up in future issues

What lessons should we learn from the Covid-19 pandemic? – Critical but Stable

"Stable", from the Latin "stabilis", from the based word "stare", meaning "to stand".

In the early stages of the COVID19 pandemic (and even now), many Intensive Care Units (ICUs) severely restricted visitors.

The reason was valid; minimise human contact and transmission of infection could be controlled. As a result, many patient updates which would normally have been carried out by the bedside or during a physical visit were done over the telephone. As demonstrated by ICNARC (1), most COVID19 patients admitted to critical care do require mechanical ventilation, high levels of supplemental oxygen or cardiovascular support. Therefore, by definition they are all unstable and critically ill. Why then did most of our telephone updates contain the word "stable"? Why did we struggle to describe the precarious situations our patients found themselves in? Why were we unable to balance the need to provide hope and convey severity to already distressed relatives?

Before COVID19, I thought little about using the word "stable" in critically ill patient updates. After all, we are accustomed to the word. Phrases such as "your [insert chronic disease] is well under control", or "your [biomarker or clinical measurement] is stable with the medications" pervade medical lingo, especially since large proportions of modern medicine deal with chronic conditions. Stability is thus associated with longevity and health. Likewise physiological stability is associated with homeostasis and normal bodily regulatory mechanisms. On a wider scale, society places an automatic value to the word "stable". A stable leadership has been quoted as a key factor in successful responses in COVID19 containment. After all, both Singapore's and New Zealand's government are renowned for stability, and their responses have been internationally recognised as positive models (2, 3). Both have only had between 10-15 COVID19 cases per million population at their single peaks (Figure 1)(4). However, even largely stable governments in Europe have struggled to control the spread of the disease, with Germany and UK seeing peaks of about 300 and 900 cases per million respectively (4). In contrast, fragile states were predicted to perform far worse in the COVID19 pandemic (5, 6). Yet, current data from both Asia-Pacific and Africa suggests a far lower infection rate than Europe or America (4, 7). Psychology Professor Michele Gelfand argues for culture as a key characteristic of success since stability was clearly not a determinant (8).

With such weight placed on a single word, and the control it portrays, it is little wonder intensivists are known to use phrases such as "critical but stable" (9). Yet, such ambiguous terms and vague phrases have been the source of interdisciplinary misunderstandings, as noticed even before COVID19 (10). More importantly, when used in patient conversations, they can be far more problematic. The term "stable" simply fails to address the long and arduous journey of critically ill COVID19 patients, nor the various levels of support they require to maintain survival.

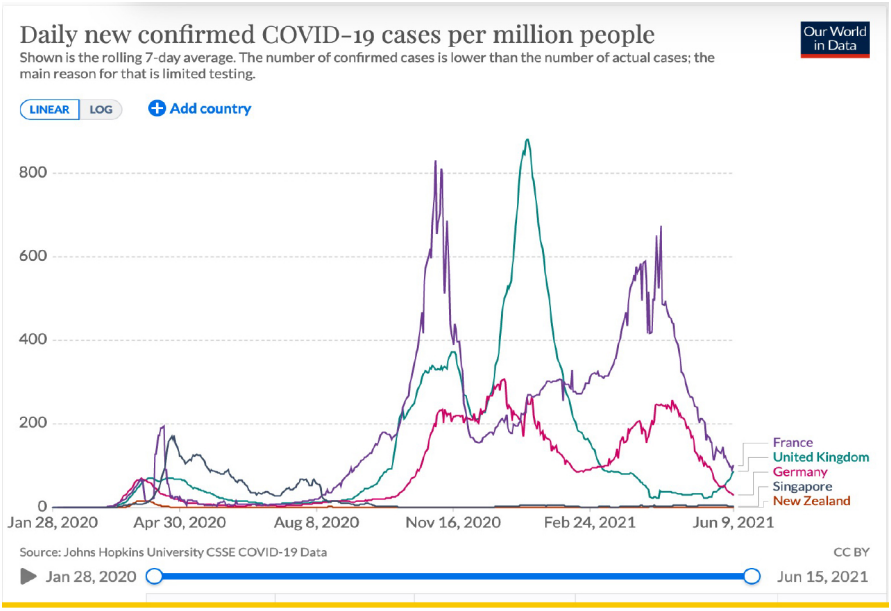

Figure 1 Graph from Our World in Data (4)

Moreover, over the telephone, families lose the usual visual and environmental input with which to frame such conversations. They would normally have seen the numerous lines and tubes, heard the multiple monitoring alarms, and felt the tepid, diaphoretic skin of near-death on their loved one. In other words, as reflected in communication studies, non-verbal cues convey far more information than speech can (11).

In fact, stability is not a key feature of critical illness trajectories. COVID19 patients' admission to critical care is characterised by instability, either from cardiovascular, respiratory or metabolic systems (12). During their critical care stay, the vast majority of COVID19 patients require either advanced respiratory, cardiovascular or renal support (1). Repetitive interventions such as proning, as well as careful titration of various interventions indicate the sometimes sinusoidal trajectory of critical illness. Even after discharge, instability does not simply disappear. For survivors, whether critically ill or not, the lingering labels, stigma and vulnerabilities outline non-linear recovery journeys (13). This is similarly demonstrated in Dale Needham's works on ICU survivorship. He and his team highlight the multi-systemic long-term sequelae of surviving critical illness, which include not only mental health issues, but also physical, cognitive and functional impairments after COVID19 (14). Thus, these oscillations between opposing feelings not only characterise the uncertainties patients feel but may also reflect the illness trajectory.

Trajectories towards the end-of-life may provide further evidence to refute the stability narrative we have been so blasé about projecting. Progressive illnesses can be understood in at least three distinct functional trajectories: sudden decline, intermittent episodic deterioration and prolonged dwindling (Figure 2)(15). While all three may feature periods of seemingly relative calm, there is still an overall decline and growing fragility which eventually leads to death. Even with the intermittent episodic deteriorating trajectory, there continues to be an impression of sudden deterioration towards the

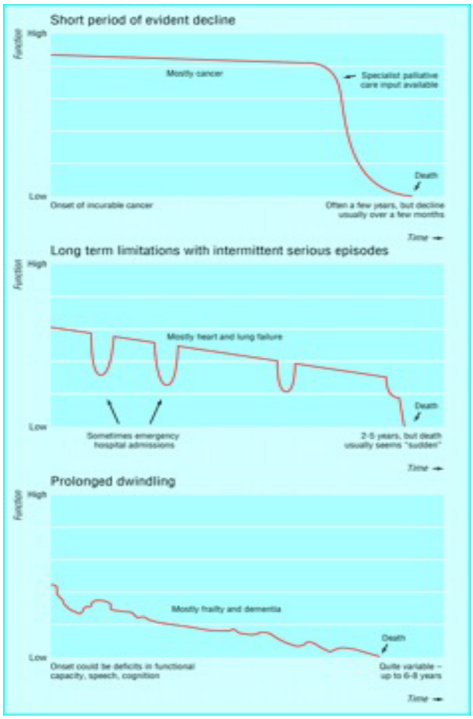

Figure 2 Three distinct end-of-life trajectories. Image from (15)

end of life. Although such functional trajectories were not specifically studied in a critically ill population, Needham's observations about the "ups and downs" of both critical illness, especially of survivorship, may in fact take a mirrored course from the palliative trajectories below (16).

Anushua Gupta is a GP, mother, and survivor of COVID19. When she was critically ill, she was put on Extra-Corporeal Membrane Oxygenation (ECMO)(17). She tethered on the brink of death for many weeks. Since I was involved in her care, I spoke to her and her husband about the communication they had when she was in ICU (18). The word "stable" was indeed frequently used during update conversations. However, without seeing his wife or the critical care environment, her husband struggled to imagine her progress, or lack thereof. He read extensively about ECMO, but as we all learn throughout medical training, physiological variables and biomarkers can only convey a limited amount about a patient's condition. This is particularly the case in ICU, where the active manipulation of physiology through machines and infusions may provide a false sense of security. After all, does not the definition of health include mental, social well-being (19), and of course spiritual too (20); aspects which are far more difficult to measure than the parameters we are used to. If Anushua's husband, himself a GP, felt unable to comprehend the severity of critical illness based on the terminology used, then what hope does the non-medical public have? Such dissonance prompted me to reflect upon the false assumptions associated with the word "stable" and to expose the unseen turmoil healthcare professionals shared with patients in a short piece last year (21).

Beyond merely communication, the absence of family during a critical care stay further destabilises the entire healthcare journey. The already problematic "post-intensive care syndrome" suffered by families is predicted to be exacerbated by the absence of visiting during the COVID19 pandemic (22). This may occur either due to the inability to visualise or recognise the severity of illness, or due to their actual absence during a time of need for their loved one. But such risks are not confined to the family. For the critically ill patients themselves, the presence of family has been shown to be a contributor to both physiological and psychological well-being and recovery (23, 24). Indeed, even from an organisational perspective, most complaints to ICU are raised by family members, relating to issues with communication (25).

Such human connection is even more important with the depersonalisation associated with the use of Personal Protective Equipment (PPE), particularly in ICU. The anonymity, ambiguity and androgyny associated with full PPE further limits the humanisation of provider-patient relationships (26), reversing the many years it has taken to move

away from a rigidly paternalistic system. Attempts such as the PPE portrait project may help to mitigate depersonalisation (27), but the resultant feeling of ostracisation and uncleanness continues to plague COVID19 survivors long after their encounter with healthcare (13).

So if "stable" is insufficient a word to describe our patients, how can we better navigate such conversations? Already, video-based telecommunication technologies have found increasing emphases within ICUs, with endorsements from multiple societies and organisations during the COVID19 pandemic (28). They mitigate the lack of visual and environmental input for families to comprehend the severity of illness. International family-centered guidelines recommend "formal, structured communication to ensure that clinical decision making is informed by a shared understanding of diagnosis and prognosis and patient goals and preferences" (29).

Clearly, face-to-face encounters can meet such recommendations far better than any video telecommunications. But in their absence, family- and patient-centered communication can still occur. Already, the use of guides and frameworks help address the expectations of families and aid clinicians in explaining and exploring complexities. An example is the Serious Illness Conversation (SIC) guide (30). Like other guides, they follow a generic format, which begins with building rapport, sharing the purpose of the conversation and probing for information.

By setting up the conversation, both parties are able to gauge the level with which to progress. After this comes the difficult part of sharing prognosis. Because this is often difficult even for experienced clinicians to predict accurately, the SIC guide advises the use of "wish…sorry" or "hope…worry" statements. This provides an honest exploration of the fine balances we are often required to strike. It increases understanding of the families and encourages shared decision-making. Following this, a further exploration of individual priorities, fears and sources of support enable a holistic approach to wellbeing, including spirituality. Finally, a summary, recommendation and check for understanding can draw the conversation to a close, even if there are sometimes no concrete answers to questions. Not only does using structured communication increase the understanding and sense of control for families in the midst of a severely turbulent experience, but it has been shown to provide greater satisfaction for the clinician too (30).

In addition, the use of imagery may be helpful for visualisation. For example, a stringed instrument requires tension for appropriate sound production. Too tight and a string will snap, but too loose and they fail to produce a sound. So too can our interventions be framed, particularly in ICU, where we constantly tread fine lines between risk and benefit. Other dynamic processes such as sine-waves, roller-coasters, vortices and spirals have all been described in ICU patient journey literature (31, 32). We too can learn to use them to help families understand the condition of their loved ones. By performing such facilitative or collaborative communication, we can further strive to empower family participation in critical care, improving overall physician and patient satisfaction, and raising the overall standard of care (33).

In the end, perhaps the most striking rebuttal of the stability narrative in COVID19 critical illness comes from the etymology of the word "stable". The fact that intensive care units around the country and globally are filled with prone or supine patients, suffering from a multi-systemic disease, reliant on machines to maintain basic physiology, clearly indicates their inability "to stand". The numerous waves and multiple variants which continue to overwhelm global healthcare systems has brought our own profession to their knees. The countless lives lost seems to have run the human spirit into the ground. The COVID19 pandemic is anything but stable, and our communications must reflect that. The absence of family does not only produce a null deflection, but negatively skews the illness journey. We must bear that in mind

when imposing restrictions on hospital visits. The need for PPE should be tempered with attempts to minimise the dehumanisation that inevitably results. So I will ditch the "stable" in COVID19, and embrace the fragility that this pandemic has exposed. For it is through our fragility that we continue to hope. Through humility that we practise selflessness needed to care for such patients. It is through instability that the human spirit clambers, climbs, and conquers, just like a patient's recovery trajectory, until humanity stands once again.

"Where there is love for man there is also love for the art of medicine" – Hippocrates

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What lessons should we learn from the Covid-19 pandemic? – a personal story

According to Albert Einstein 'out of adversity comes opportunity'. The title of this essay brought this quote to my mind. Covid-19 has had seriously devastating effects for so many people, the suffering feel insurmountable at times.

Whilst acknowledging this I wanted to explore if there are any positives we could draw upon from this tumultuous time and what we can learn from this. I have taken the invitation to reflect on what I have personally learnt about myself in the unexpected and unnerving period of history and how is may have led me to be a better person and doctor.

Firstly I wanted to reflect on how the lack of choice has taught me that the world we live in can sometimes not be conducive to a calm mind. A calm mind is such a useful tool for a doctor. At home, from the moment we wake up to the moment we go to sleep there are choices, choices, choices. Which friends should we meet with today? Where should we have lunch? What activities should we do? Where should we go on holiday? The list is endless. At the beginning of 2020 all these choices were taken away almost overnight. You can't meet with anyone, in fact you can't touch anyone, and actually you can't get within 2 meters of anyone! We are not going for lunch and as far as an activity goes will a walk do? Holiday? FORGET IT!

After the initial shock, for the most part, I found it surprisingly refreshing. I appreciate this is not everyone's experience. I am privileged I had a home to isolate in, I had my children to keep me company and financially I was not affected. My point is that life was stripped back to its very basics – spending time with your house hold and doing things you were previously too busy to do, was in fact enjoyable. The lack of choice made for a less busy life and a calmer mind.

This is not the first time I have learnt this lesson. The last time I experienced such a lack of choice was when I lived in a monastery in Ghana whilst I was volunteering with the mental health team in Koforidua Central Hospital. In the monastery the days were highly structured with set times for meals and other activities. There was no TV or radio and I didn't take a smart phone, so I didn't have to choose what to watch, or what to read or who to WhatsApp. Paradoxically this lack of choice was liberating. On returning to the UK I forgot how important this is for me as person and a doctor and I was swept back into a busy life all too quickly.

The idea of choice being a burden rather than a positive, reminded me of an experiment I read about years ago. There was a class of photography students who were split into two groups. At the end of the course each group was allowed to choose, print off and frame a photograph to keep. One of the groups was told that they could take the photograph home and after a month if they felt so inclined they could swap it for another photograph. The other group was not given this option. A month later the class regrouped. The students who were not given a choice to exchange liked their framed photograph but those who were given the option to swap felt a dissatisfaction with their work – the light wasn't right, the composition was off and therefore they wanted to swap. There is an illusion that choice makes us happier but as this experiment shows it doesn't necessarily make us more content.

Less choice can be a source of calm and we could all do with a bit more calm in life! When I feel calm I know I am better at my job. I get panicked less easily when faced with complex or urgent clinical or managerial scenarios. I am able to problem solve more effectively. I can acknowledge and explore transference and counter transference better in my job as a psychiatrist. I am also able to attend to my colleagues needs and notice if they are struggling, whether that be professionally or personally. Don't get me wrong, I am desperate

to go on holiday and I have thoroughly enjoyed eating out in restaurants again, but I hope that I remember the principle that too much choice is not necessarily a good thing.

The second point that the pandemic has emphasised to me is summed up in this quote many of you may be familiar with from John Donne, a meta-physical poet from the 16th century:

'No man is an island, entire of itself;
Everyman is a piece of the continent
A part of the main'

Patients, our colleagues and ourselves do not exist alone, we are part of system - work systems, family systems, societal systems. As a result we need to see a person in their entirety with all their surrounding baggage. The pandemic has taught me that our colleagues, who have been working tirelessly, have so many other things going on under the surface. They have been battling home schooling, working from home, spouses furloughed, financial problems, isolation and potentially loss of a loved one due to Covid, to name but a few. It is important to acknowledge this and support each other, not just because it will make us all more productive, which benefits the patients but also because it is the right and kind thing to do. Whilst sitting at my computer to write this I have received one of our regular Covid update emails and within it this message is highlighted in bold:

'We are caring and compassionate
We are respectful
We are honest and transparent
Don't lose sight of who we are'

The pandemic has taught me, even more than before that we need to look after each other, patients and colleagues alike.

Finally, the pandemic has urged me to reflect on other epidemics and pandemics that have happened globally. I do not want to take away from anyone's suffering here in the UK. It has made me feel lucky as a doctor and as a person that not only do we have an NHS but we have (relatively) good infrastructures and (relatively) good support organisations. I was in Ghana just after the peak of the Ebola epidemic. I remember at the airport standing in long lines to get my temperature checked before leaving the country. I knew this was because of Ebola but shamefully it is not until Covid-19 in the UK that I have really thought about what Ebola meant for the country I was visiting and the people living in it. Ebola was devastating for West Africa. It did not only kill vulnerable groups but young fit people. In that feature it was similar to the 1918 influenza pandemic where there was a high mortality rate for healthy individuals including those in the 20-40 year age group. The consequences of Ebola were far reaching. In terms of mental health there was a significant increase in cases of anxiety, substance abuse, behaviour problems in children and gender based violence. There was a huge amount of fear and stigma in the population. There were financial implications and of course much morbidity and mortality. As a psychiatrist the pandemic has taught me to be less introspective and to consider what is happening with mental health globally and to try to understand the interactions between physical and mental health.

I am currently working in the substance misuse service. There are consequences of the pandemic which I do not think are seen by the general public. For instance there was no inpatient alcohol detoxes, patients have died whilst waiting. It is suspected that methadone overdoses were increased possibly because socially distanced supervised consumption cannot be accommodated. Many clients are not getting reviewed face to face and the social isolation and damage is immeasurable.

I think Einstein was right. Out of the adversity I have had the opportunity to learn, learn about myself. I have learnt that choice is a blessing and a curse and that a calm mind helps me to make better decisions. My calm mind helps me t o look after my colleagues and to see the

challenges they face within the systems in which they exist. The pandemic has taught me that there is a lot of unseen suffering. It is unseen because we choose not to look for it or because we choose not to acknowledge it, as I shamefully did with the Ebola outbreak in West Africa.

Further reading

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Sophie Quarshie

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