If I was Minister of Health...

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By PD d'Arienzo

... I would not rely on my medical knowledge to make decisions. The reason for this is simple. To create a sustainable, equitable, and effective public health system, we need leaders that do not claim to have the answers but who seek them in understanding and empowering others. The hard work in making healthcare work for everyone will not (just) lie in addressing the effects of years of chronic underfunding, but in cultivating a sense of curiosity that is the reversal of a centralised, one-size-fits-all approach of healthcare. So, in the following, I will outline how the willingness not to be an expert - what Zen practitioners call *beginner's mind* - could transform healthcare for the better, serving local communities, improving patient outcomes, and making the NHS a better place to work.

Care beyond compliance

In the UK, the most common causes of death are non-communicable or chronic diseases, such as heart disease, dementia (leading cause among women), stroke, and cancer[1]. This means that the main challenge for the National Health Service (NHS) has been to balance needs for prevention and treatment with cost-control, requiring alignment of health professionals and compliance of patients. Both of these have been difficult to maintain; as much as 25% of medicines prescribed for chronic conditions in England are not taken as directed, costing the NHS nearly £1bn each year for just five of the most common diseases[2]. Among practitioners, uptake of National Institute for Health and Care Excellence (NICE) guidelines is notoriously slow, and British GPs were shown to trail their international colleagues in adherence to cancer referral timelines[3].

And so we have developed a sense of expectation - both of our patients and colleagues - that people need to be living agents of the best available scientific evidence. When we see people falling short of these expectations, our natural response (certainly mine) is a mixture of disbelief and annoyance. I often catch myself struggling with patients who fail to maintain reasonable control of their condition by taking their oral antidiabetics or their insulin as directed and inevitably develop one or the other complications who lead them to have to commit to an inpatient admission. As an expert, I have difficulties coming to terms with the fact that even the best medical advice may have little effect if we don't find in the patient a

strong ally. Another way of putting it is that **healthcare today is a mass-cooperation exercise.**

Viewing health through a manichaean prism of (non-)compliance, however, comes at a great cost. It stifles our sense of curiosity and care about the people and communities we serve and work with. Instead, assuming that we already know, we do not do the hard work of understanding them, their values, personal or cultural histories, motivations, and needs. Without the intention to understand, people who we perceive to be non-compliant take on the shape of an obstacle.

This is part of the appeal behind big data, artificial intelligence, and nudging in healthcare. Defining public health problems with a mouse-click rather than having to engage with the complexities and contradictions of real human beings suits the impatient implementor. To algorithms, people who feel ashamed about their HIV diagnosis and therefore prefer not to take their pills or go to their appointments are equal to those who care for their health but still struggle with the time-consuming exercise of controlling systematically their eating and exercise habits - they are all non-compliers. Similarly, the popularity of nudges with policymakers in recent years has made most of the public communication on health a one-way street. Despite the advent of shared decision-making and patient and public involvement in the NHS, too often the underlying question driving engagement is: how can I best convince you that I am right?

Covid-19: A Tale of Two Countries

This foreclosure to the possibility of learning from our patients and communities has undermined public trust and exposed its fragility in the current coronavirus pandemic. Working in a hospital in London's East End, I have experienced first-hand how we are failing (to reach) people from minority ethnic communities. There is now evidence that people from a BAME background have worse outcomes from COVID-19 pneumonia than the white British population (Public Health England, 2020; Apea et al, 2020). We have to go above and beyond to ensure that disadvantages which vary in nature from biological (e.g. high prevalence of diabetes in populations of South-Asian ancestry) to socio-economic (how daunting is it to make a 111 or 999 call for an frail, elderly person whose first language is not English) do not translate into worse disease outcomes[4,5].

Both nationally and locally, it took too long to get the key messages across. For my patients with South Asian roots, this needed more than translating "Stay Home, Save Lives" into Bengali, Punjabi, and Tamil. It would have required a deeper understanding of the realities of their lives and livelihoods, driven by genuine curiosity and care. Researchers and policy-makers have long spoken of so-called 'hard-to-reach communities' in relation to underrepresented groups. To me, this is a complacent term. It puts the onus on the service user rather than on building a foundation of trust necessary to engage them.

Amid a new drive towards big government programmes not seen since the Great Depression, it might be easy to miss the other tale that has formed part of the coronavirus response in our communities. Across neighbourhoods in the UK, over 4,000 mutual aid groups have spontaneously sprung up to support the most vulnerable - all without central coordination and not much more than a basic template. (https://covidmutualaid.org/) In the early days of lockdown in March, my partner helped setting up a local group.

"It all began by joining a WhatsApp group with more than a hundred people. We all wanted to make sure that, if the virus hit us hard, nobody would be stuck sick at home or too frail to carry shopping bags", he tells me. "The question was: how do we organise our area, its volunteers and those in need? And, in a way, the epiphany was that we don't."

Within a day, they had launched a GDPR-compliant survey to register volunteers and printed simple flyers asking for what people needed with the handwritten contact details of a local volunteer. "All that the temporary admin team did was ensure no streets were uncovered. And then we left it to mini-teams covering no more than a few streets. At no point was there a central coordination of requests. Instead, people forged new relationships with their immediate neighbours through non-transactional giving." All of this happened before the government started sending food packages to those shielding. As for the huge WhatsApp group, it is now primarily used to circulate a weekly menu of food deliveries from a blend of private supercooks, soup kitchens, and local business.

To those of us who have been fighting coronavirus on hospital wards, this is both an unbelievable and familiar story. Familiar because also in my hospital, suddenly things were very simple. After years of unsuccessful lobbying, paper notes and paper requests forms were scrapped and converted into their equivalent electronic form. Or, the incredibly laborious way of dividing new medical admissions between different teams was replaced by a simple, ward-based model of care. Unbelievable because as doctors we are endowed with a huge

blindspot: we see people for whom things have gone wrong, after they have gone wrong. This means we do not often see people caring for themselves and others in the community. This feeds cynicism, and in turn makes us less likely to see our patients as people whom we could learn from. Yet our own experience of leading our local wards and trust through trying times, taking charge, and making things work better for our patients should give us more trust in our patients' abilities to transform *their* lives.

Public service is always local

As part of a covid recovery strategy, we need to tap into both the intrinsic community spirit that mutual aid has demonstrated and the purposeful action of professionals through adopting new care models. One of them is the hard-to-pronounce Buurtzorg (Dutch for 'neighbourhood care'), through which self-managing teams of district nurses provide both medical and supportive home care services[6].

Buurztorg was launched in 2006 in the Netherlands to respond to challenges that sound all too familiar: fragmentation of care and a demoralised workforce. For founder Jos de Blok, the answer lay in self-management. At the core of this strategy is enabling people to manage their own lives as much as possible. Buurtzorg nurses actively rely on patients' capacities and motivations, as much as trying to bring in the informal networks including relatives, friends, and local charities around them[7]. But the idea of self-management also applies to the workforce. Nurses care together, as a team of up to twelve members, for a relatively small group of patients (maximum 60). Keeping the numbers low enables workers to make collective and/or autonomous decisions to solve matters. Each team only operates at the neighbourhood level, which empowered nurses to go beyond the mere nursing and medical management of their patients. Buurtzorg's nurses are more like "health coaches", who create sustainable solutions leading towards prevention and care independence[8]. Leveraging existing support systems, "they are available round the clock and – working closely with GPs – they organise all the supporting care, drawing in families, friends, and volunteers. They see themselves as community-builders"[9].

The home care social enterprise, which now spans more than 850 teams has risen up to the challenge in achieving consistently high patient and nurse satisfaction, lower staff turnover, reducing costly hospital stays[10]. What Buurtzorg illustrates is that healthcare works best if it

stands on a foundation of trust and autonomy, empowering both patient and carer. To the professional empowered to do a whole job, the whole person matters[11].

Now, the UK is not the Netherlands. When I spoke to Martin Brendan, managing director of Buurtzorg Britain and Ireland, he openly admitted challenges of bringing the model to the UK. What some health leaders have misunderstood is that giving your frontline staff the tools to do their jobs is something very different to leaving them to their own devices to somehow prove that you didn't make a mistake by entrusting them with their tasks. "We've revealed great potential but you must start with clarity of purpose and strong leadership commitment, and create an enabling and supportive environment for practitioners to succeed with self-management," Martin told me.

This, to me, is a question of right engagement as a leader. While we should have *national* strategies to fight cancer, fund dementia research, and, yes, train and retain a world-class health workforce, public service is ultimately always *local*, drawing actively on communities rather than just seeing them as landscape. It would therefore also be wrong to simply call for the Buurtzorg model to be the blueprint for a health and social care reform.

Beginner's mind

In the 2020s, UK health policy does not merely need a new manifesto and spending promises, it needs an upgrade to its leadership philosophy. We do not first and foremost need 40 new hospitals in Britain, but self-caring neighbourhoods and well-trained professionals in locally responsive public services, supporting healthy populations. To move to care beyond compliance then, we must also be prepared to say: what works in Wigan, might not be right in Reading. As Zen master Suzuki Roshi writes: *"In the beginner's mind there are many possibilities, but in the expert's there are few."*

Creating this future for healthcare thus begins with curiosity and care. This is why I believe the most powerful question that any minister of health, nay, any leader, can ask is: **how can I help?**

And then listen.

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