You won't realise what you've had until it's gone The vanishing of communities in our healthcare

David Zigmond
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Personal relationships are the essential building-blocks of communities, yet these are increasingly imperilled in our current increasingly systemised healthcare delivery systems.

This interview briefly explores the origin and nature of this impoverishment and what we might do.

Simon Duffy (SD), Citizen Network

David, it's been five years since we published The Perils of Industrialised Healthcare,

where you argued strongly for the retention of personal bonds and relationships in a

healthcare system that is increasingly industrialised.

I gather your views and conviction have not changed ...

David Zigmond (DZ)

No; they've got stronger!

SD Why is that?

DZ Because the problems I wrote about five years ago have got *worse*. Our medical

and information technology continue to improve, but our personal connections,

understandings and comforting inclusions have often reciprocally perished. So our

healthcare contacts are mostly better physically equipped, yet more humanly

estranged ...

SD How is that manifest?

Well, generally, we can readily see how the levels of dissatisfaction and distress

among both patients and healthcarers has much increased over the last couple of

decades. And that kind of insecurity and unhappiness makes for increased illness –

or at least dis-ease – in patients, and for demotivated inefficiency in the healthcarers.

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A lot of people put all that simply down to lack of funding. Do you not agree?

Only partly. Yes, I certainly agree that inadequate funding is a core problem. But I want here to talk about other core problems...

Anyway, the result is that although *technical treatments* are often better (if you can manage to get in the right queue!), the *personal care* is usually worse, now even indiscernible. That's a fundamental theme I'll keep returning to.

But a lot of people seem to think that it's only the technical treatments that truly matter; that the kind of personal care you champion is a mere nicety, a side-garnish. Is that mistaken?

Oh yes! This misconception is both root and major branch of so many of our difficulties...

How so?

Well, there's a lot to consider, so I'll try to be concise...

First, all kinds of treatments work best when both patient and doctor consider themselves in a caring – personally resonant – relationship. This has been recurrently and clearly demonstrated over many decades...

(Just to clarify: I'll often talk of 'doctors' – because that's what I am – but the statements I make are often equally true of the other healthcarers: nurses,

physiotherapists, psychologists/counsellors etc.)

Not all treatments, surely?

Actually, I said 'all kinds', not 'all' – so I agree.

So what's the distinction?

OK. We must first acknowledge that there are some clinical scenarios where the personal relationship becomes relatively unimportant or even impossible. For example in acute surgical emergencies, CPR (resuscitation), mass vaccinations... In all these the procedure must be determinant. But after the procedure is done it is the nature of *care* – both between individuals and together as communities – that will best enable palliation, healing and sustainable recovery. Again, there's much research from many sources over many years to show this.

Give us an example of the relationship between the two.

OK. Someone, 'S', collapses. Without knowing much about S, the emergency 'procedural' services efficiently relay S to a cardiac lab where an acute coronary artery occlusion is dramatically relieved by a stent insertion. All of that is generically – and correctly – procedural.

Yet prevention of such a problem, and then sustainable recovery from it, is a very different matter. S's experiences, relationships, choices and behaviours massively influence the longer fate of the dramatic episode. And these are *personal* –

idiomorphic – matters most accessible to personal care, but mostly unreachable to procedural – generic – treatments.

So how big, how important, is this personal care challenge in our current system?

Oh, very! It's actually the larger part of what our NHS is faced with...

Really?

Yes, really... although a lot of people don't see that...

Don't see what?

OK. Consider what primary and mental healthcare – who provide, by far, the majority of NHS consultations – encounter as most of their work:

perceived problems of maturation and development; stress-related/psychosomatic conditions; disorders of behaviour, appetite, mood and impulse (BAMI); incurable, so chronic, illnesses; irreversible or irreplaceable age-related organ and musculoskeletal failures; palliative and terminal care.

These are what account for most NHS activity – so they are very common, some (almost) inevitable. Yet none can be swiftly and decisively 'fixed' by procedures, treatments, though treatments may be partially helpful when skilfully integrated with personal care.

So you use two important (I think) words there: 'skill' and 'integration'. What do you mean?

Well, they both refer to creating the best balance between the personal and the medical. So the practitioner needs to know – and be interested in – not just the science of the condition but how to apply that to *this* person, in *this* situation, *now*. Individual human context... Together these make up 'pastoral healthcare'.

And that requires a balancing act between (objective) scientific knowledge and (intersubjective) emotional intelligence...?

Exactly! That's the skill – the art or humanity if you like – that should constitute much of our medical practice.

Yet for years you have campaigned about the erosion – the loss – of these skills and therapeutic opportunities. What has happened?

Increasingly, over the last half-century, our culture has become victim to our own technological victories, blinded by our scientific successes. So in many ways our progress has meant our victories are pyrrhic!

Oh dear! I think you're here biting off more than we can chew in this interview. Can we just focus those grand notions on our healthcare?

OK. Recent decades have seen massive advances in medical sciences and their technologies. Many previously lethal physical conditions have become treatable,

even curable.

The problem is that this evident and massive success has blinded us to its limits: our technological approach may be very powerful for cure, but often inimical to care.

Because?

Because care requires personal knowledge, familiarity, trusting and affectional attachment, resonance and understanding. There are substantial yet subtle skills and understandings required to achieve these. But first we have to work in a system that enables us to get to know one another: communities of people.

Technology is operating on very different territory: cyber-networks that replace personal interchange.

So what has happened?

Well, with our increasing power of medical and digital technologies we have lured ourselves into a kind of hubris that I call *Technototalitariansim*.

I won't be saying that! What do you mean?

The problem is that one thing replaces another ... unless we're very careful. So the more the practitioner submits to institutional algorithms, the less headspace and heartspace is available for *this* person *now*. We are left with a system where no-one-knows-anyone-but-just-do-as-you're-told-and-follow-the-algorithm.

The widespread loss of headspace and heartspace is a major cause of increasing professional discontent in its many guises – recruitment, burnout, opt-out, kicked-out, conk-out: serious illness and addictions ... suicides.

So that headspace and heartspace is good for the practitioner as well as the patient?

Yes. This is often difficult work: both patients and practitioners are alike in needing a sense of personal meaning, significance and resonance in their interactions. Of course the roles are distinctly different, if complementary, but the deeper human needs are shared ... and they are always there!

Yet our industrialising reforms – our Technototalitarianism – has so marginalised any satisfaction of these deeper human needs as to make them nearly extinct.

Increasingly our managing systems have regarded the personal aspects of consultations as irrelevant or, worse, undesirable.

The underlying idea – the folly – is to attempt to make *all* our healthcare into a mass-production precision industry – similar, say, to car-manufacture or commercial air travel.

Ah! your word 'commercial' there. We haven't talked about that yet.

Yes, introducing 'market principles' into our NHS has greatly increased these problems.

Why? What's happened?

Well, in the Thatcher-era the NHS was corralled into a broader neo-liberal agenda which has been expanded by successive governments since that time...

Can you explain what that meant?

Neoliberalism is the belief that almost any human activity or utility functions better if it is both commercialised and privatised. The assumption has been that Darwinian competition sharpens intelligence, fuels motivation and brings business-like acumen to large systems. Likewise the financial incentivisation of increased earnings and profits.

So what happened?

Hm! Overall, it hasn't worked – it has depleted the very things it was meant to assure and boost: efficiency, morale, motivation, esprit de corps...

Why was that?

Because caring for humans has only limited similarity to manufacturing objects or utilities. Manufacturing and marketing washing machines is very different to comforting or healing fellow humans ravaged by loss, dispiritedness or chance. Few of us care with greater heart and attention because we are paid more, or managed with greater severity. Yet not understanding that profound distinction accounts for the impoverished, and then impoverishing, healthcare psychology of the neoliberal

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reformers.

So you're saying that executives and planners of our healthcare over the last few decades haven't understood adequately what makes people 'tick'.

Essentially, yes. It seems to me that they have been in thrall to some traditional political and economic theories that hold that we can get the best out of people by employing sticks and carrots. And then eliminating the DSRs (Duffers, Slackers and Rotters) by ratcheting up our rules, regulations and surveillance.

All of that is now understood to be of very unreliable effectiveness in manufacturing industries; even more unreliable in our criminal justice system. In healthcare such approaches are worse still – they are all too often destructive: alienating, demoralising and demotivating. Their over-application is a profound error because the quality of healthcarers' work is deeply dependent on their vocational and personal satisfaction: generally, *if they like their work they will do it well*.

You've written extensively of 'REMIC'. Can you explain what that is?

Yes, REMIC stands for 'remote management, inspection and compliance'.

Since the digital revolution the power of all authorities to ensure compliance and obedience has been unprecedentedly increased. Instruction, regulation, surveillance, sticks and carrots ... all can now be implemented rapidly, accurately and on a mass scale. Our healthcare – this vast and complex network of services – can now be monitored and commanded remotely. Increasingly the experience of healthcarers is

akin to being tracked and directed by a distant, unknown and unseen Air Traffic Controller. This is key now to our NHS Technototalitarianism...

But that's not all bad, surely?

I agree. Such REMIC can be a powerful guarantor of activities in public health, established medical and surgical procedures – activities where little or no variation is required. It's a bit like needing a public police force for our personal safety.

So what's the problem then?

The problem is the scale and the application. More of something 'good' is not necessarily better; it may be worse. There is a profound difference between a police presence and a Police State. The folly of the now very powerful REMIC regime is that it is so often experienced as an overbearingly and indiscriminately pedantic or draconian parent. All too often that will inhibit more than enable. An intimidated workforce will learn to tick-the-boxes-and-cover-up. 'We've all got to play the game and feed the Monster' is a common refrain, heard most frequently in the areas of pastoral healthcare least suited to procedure and protocol – general practice and mental health.

Tellingly, these are the services with the greatest staffing discontent and instability.

Overall, has REMIC been at all effective?

Overall? No – there's very little, if any, evidence of this.

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What about the ineffectiveness, the harm?

Rather more evidence for these. Despite the enormous cost of REMIC, there are legion and increasing failures of the NHS – in service provision, safety and satisfaction. These are clear for all to see, and clearly indicated by measurable indices.

The increasingly discredited Care Quality Commission (CQC) has made some spectacular errors in favourably-rated institutions and practitioners whose compliance-performance concealed egregious neglect or malpractice: 'Playing the game and feeding the Monster' becomes a common, stealthy survival-skill.

More significant evidence? There are very few (if any) veteran doctors who think that REMIC has brought greater safety, competence and motivation to their work.

They think, rather, that the compliance-demands and the threatening spectre of REMIC has distracted and subtracted from their more mindful and better practice...

So what roles, if any, should regulating and accountability have?

Well, clearly there must be some! This is true for all individuals, families, groups and organisations. The important questions follow: what? who? when? how much? and so forth.

The current errors and follies of REMIC come from indiscrimination, then excess.

Can you give a brief example of that?

Yes, Dr D (known to me) is a highly-stressed under-resourced GP. Despite this he has managed (with difficulty) to maintain good relationships with staff, colleagues and patients. There has never been evidence of malpractice, substantial incompetence or questionable probity.

Nevertheless he is anxiety-distracted and time-depleted by the imminent REMIC-commanded CQC inspection. 'It's got worse every year: I have to spend more and more time compliance-ticking, logging, data-gathering, spread-sheeting, certificate-scanning... This isn't about my real competence; it's about their (abstracted) need for compliance...', says Dr D.

Indeed, a triumph of Technototalitarianism! This is what happens when intelligent questions of discrimination are not applied. Wise authorities are very mindful of this; we can see the effects of neglect of this principle elsewhere. For example, the over-strict parents who, early on, gain short-term craven compliance from small children, but eventually will garner overspilling defiance, passive-aggression or poor self-agency when grown. Or, say, the Police employing their sometimes necessary right to Stop and Search: what happens if they overdo this? The results are similar to the over-adapted children, yet even more dangerous.

Cleverness may be about how to do things: wisdom is about *how* and *when* to do them (or not!).

You've also written and campaigned a lot about the damage caused by our excessive

investment in scaling-up ('Gigantism') and our overuse of digital technology (IT and – increasingly – AI). In a way I see these as variations on a theme.

Yes, both of these, unless we are very careful, can add to the kinds of personal alienation, demotivated loneliness and lost personal agency that any kind of industrialisation can bring. This is particularly true of healthcare, which is so often 'people work' ... and so even more true of general practice and mental health – the anchors of pastoral healthcare.

So much of what I've got to say about Gigantism and digital technology I've already expressed about industrialisation in general, and then marketisation. Gigantism and digitalisation are powerful allies, synergists, to these.

OK. Gigantism, scaling-up. What is it? And what's the problem?

Well, it's now, increasingly, a must-do in our ever-more automated world. 'Get bigger or get out!' With larger scale we can, often, avoid duplication and variation, reduce management and premises costs and complexity. We can federate, centralise, optimise highly specialised skills and equipment... So the arguments are for gains in economies and operational efficiency...

So Gigantism can bring great advantages?

Yes, definitely. But only sometimes. There are other healthcare endeavours that are stymied by Gigantism. It is a humanly and economically expensive error for our reforms not to distinguish between the two – to almost always favour bigger-is-

better plans.

Can you give an example of each?

OK.

Gigantism is the best way to provide very specialised treatments and investigations that require very particular technical experience, skills and equipment. For example Cardiovascular or Neurosurgery, major trauma, Intensive Care. Pooling and centralising expertise and resources with these clearly has advantages over small, more local centres that cannot match this.

But such federation, centralisation and pooling is far less applicable to general practice; here Gigantism is often harmful. This is because – as we've seen – this kind of practice is as much people-work as medical science. It is more often about pastoral healthcare than mere technical protocols. This depends on getting to know and understand the lives and experience of individuals. And that depends on a high level of personal continuity of care, where both doctors and patients feel part of a community of people-who-know-and-who-care. For decades this was a sine qua non of our better general practice; it was our humanity-dynamo.

And now we have a serious predicament. Our industrialising reforms have, almost everywhere, emulated competitive manufacturing industries. Gigantism has been necessary to expedite marketisation and REMIC. So almost all smaller practices have been frog-marched into closure or coerced federalisation into unprecedentedly large practices. These are now further amalgamated into Primary Care Networks, often

serving populations a hundred times greater than the small practices they have swallowed. Gigantism has cleared away personally sentient communities.

It is inevitable now that these enormous practices are staffed by a Lonely Crowd whose cybergovernance is conducted by the unspoken yet ubiquitous maxim: Noone-knows-anyone-but-just-do-as-you're-told-and-follow-the-algorithm. In this Lonely Crowd personal continuity of care is very rare indeed. Patients and healthcarers are unhappy and restive. Diagnostic and therapeutic opportunities are lost in the depersonalised and overloaded mêlée. The inefficiencies mount; the costs soar. Unmanaging managers are firefighting...

That is a snapshot of what misplaced Giantism has brought to our depersonalised so depastoralised General Practice.

I think you have similar observations and cautions about IT, and now AI. Is that right?

Yes, very much, so I think I can keep this answer shorter!

Of course AI has incomparable advantages in terms of speed, clarity and massproductability of signal, durability, accessibility and transmissibility of data, and so forth. Some of this is unproblematically helpful, as with some applications of Gigantism.

Also similar are the excesses and misplacements. These happen for similar reasons of unscrutinised expedience. We humans hardly ever invent something of great use without subsequent great overuse... And, as I emphasised before, things displace

one another ... things get crushed, driven out, lost.

So what's happened in healthcare?

It's best if I give some examples. We're running short of time so I'll list a few:

- Doctors spend more time now interacting with computers than with patients.
- Patients often comment on how a doctor's attention and interest is more on the computerised data and instruction than on what the patient wishes to express.
- Computerised records are clearly more readable and instantly accessible across our networks of healthcarers. This sometimes has clear advantages (eg emergency care elsewhere), but it has also been an important factor in the expedient displacement of personal continuity. ('It really doesn't matter which doctor you see: they'll all have your records…').
- This also means doctors are unlikely to get to know their patients this leads
 not just to a loss of diagnostic accuracy and efficiency, but to substantial
 losses of therapeutic influence and its pastoral healthcare satisfactions.
- IT, and now AI, can apparently replace face-to-face reception or consultation work, or at least make these virtual. Management may decide that this is economic and ergonomic. Yet many patients (myself included) want personal contact and attention, from first contact. We do not want an algorithm-greeting and then auto-segue to a machine-defined pathway. The reasons for this are subtle yet seminal: they are essential to pastoral healthcare.
- Computer-relayed data, missives, requests, instructions, briefings, reports

and general FYIs keep increasing. More and more they refer to patients or practitioners the viewer does not know (due to Gigantism etc). Many hours of such mandated and alienated screen-gazing and moused keyboard-tapping is dizzyingly debilitating – 'Email Encephalopathy'. Few doctors like such work.

Constant submission to 'necessary' computer codes and algorithms changes
the way humans think and behave: practitioners generally become less
interested in, and less able to handle, the encoded, the ambiguous, the
unspoken and the unevident. These may be essential keys to understanding
and bridge-building, especially in pastoral healthcare.

It is not just the machines that cannot function in this area: eventually the human operators emulate the machines!

 Computer signalling is not human communication. Even with imaging, the interchange struggles to escape from the transactional, to plant itself in the relational.

So Zoomed or texted consultations should, in my view, be the preference of the *patient*, not the expedience of the practitioner or institution.

Extending this notion should caution us: the greater our use of IT and AI, the greater the imperilment of communities: our groups of familiar people whose lives, faces and voices we get to know, whose experiences and struggles have personal meaning, importance and value for us. Contracted, cybernated networks are very different from human communities.

Currently real communities are becoming etiolated as they are bypassed and displaced by our brilliant machines...

I have many other examples, but I'm aware of the time...

Quite! But – briefly, please – give us one example of where IT can be used with greater discrimination and reduction.

OK. Restore the direct personal engagement during consultation hours of receptionists to answer the phone and greet patients arriving. Only delegate these tasks to answerphones, algorithms and digitalised questionnaires when out of hours, or with patients who opt for them.

There are immediate costs to this human-first approach, but subtle and growing benefits that offset, and surpass, that cost.

My own small practice was evidence of this.

Well, David, there were some other questions which I'd suggested in an earlier discussion. In some ways I think you've already addressed some of them...

In the few minutes we have left I wonder if we can tie off some of my loose-end questions.

Let's do what we can! Just some quick-fire responses. Very incomplete. Ping-pong!

OK: the best relationship between healthcare professionals and local communities and neighbourhoods?

Restore named GPs working in smaller, stable practices. Do not replace GPs with subcontracted unter-doctors. Avoid megapractices and commercial/corporate takeover. Restore GPs as personal anchoring hubs = continuity of care.

Why does trust matter? And how is it best achieved?

Trust is always important – in experience and outcomes – even in very procedural healthcare. It's generally best achieved in workplaces that are not commercially controlled and heavily regulated, and where the workers are cooperatively colleagueial rather than corralled by dictate. Personal continuity of care, whenever desired and possible, is a great trust-promoter.

The best social conditions for good mental health?

Much I've already mentioned: resonance and inclusion with known others, significance with and for others = community, a sharing of consciousness – dreams, joys, fears, hopes, sorrows. Time and care for others' pains and losses.

The best meaning of regulation in healthcare? How do we achieve it?

Emulate the best kind of parental authority: clear yet flexible – so age, situation and child attuned. Firm but rarely punitive. Vigilantly encouraging safe autonomy. Knowing (mostly!) when to step in and when to let go. Coercive only as last resort; so rarely. Respected more than intimidating. A good model, but not for obeisance or cloning.

That's 'best regulation' and, I think, how to do it ... in healthcare anyway!

One last question: why are physical and mental health connected?

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Ugh! Such a complex question, and here so little time to answer ... lengthy learned tomes have bequeathed us more mystifying questions than answers... I prefer the question 'how' to 'why': it is more answerable. So that's what I'll talk about!

A few pragmatic thoughts:

- Mind and body have a semi-autonomous indivisibility: they are different aspects of the self that sometimes can control and synchronise their 'twin', and sometimes not.
- Benefiting or harming the one, is likely to similarly affect the 'other'.
- Generally it is good to consider the two as a synergistic system, though there are great variations in how we do this. Here is an example:

P is having a heart valve replaced by a surgeon, S. Two weeks prior to this operation, P's much-loved husband suddenly died, leaving P feeling perilously vulnerable and afraid.

S knows this but does not heed this emotional fragility while P is unconscious and he is carefully inserting and securing the prosthesis. However, S tells the supervising nurse, N, that P's surgical recovery will be greatly helped by sensitive responses to her complexly disturbed emotions. P does not know of N's briefing by S, but she awakens to a sense of safety, resonance and inclusion from those around her.

Here are specialists creating, and working with, a community that generates its own mind-body wisdom, its own emotional literacy. In this scenario, here is a good team, here – for a while – is a human community.

I think that's the place and time to end, don't you?

Yes, we've certainly covered a lot!

For those interested in what we can do to remedy REMIC, Gigantism and commodified industrialisation, Section 10 of our The Perils of Industrialised Healthcare provides a readable synopsis.

Many of David's articles are on Citizen Network's website, <u>citizen-network.org</u>.

A final word from Henry Marsh, a veteran neurosurgeon, looking back to his earlierera hospital experience:

'It [the hospital] was built on a human scale. I knew all the staff – not just the other doctors, but also the nurses, the physios, the porters and cleaners. I think all of us at all levels had a real sense of belonging and personal responsibility for what happened to our patients. The hospital was famously efficient...'

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Interested? Many articles exploring similar themes are available on David Zigmond's Home Page (http://www.davidzigmond.org.uk/david-zigmond-archive-homepage/).