Shame:

healthcare's unmeasurable undertows

David Zigmond

Medical and mental healthcare have become increasingly transmitted by notions and language of the explicit, the designatory and the measurable. What happens to the rest of our humanity? Three vignettes from different decades illustrate.

We never forgive those that make us blush

– Jean François De-La-Harpe (1770), *Melanie*

Shame, a near-universal accompaniment of human compromise, often generates major distress, yet rarely finds direct language. How, then, do doctors – now so often seen as 'fixers' – deal with such an elusive problem?

1. Cyril

January 1970. A small hospital in the Midlands.

Cyril, aged seventy-one, had never before – apparently – erupted with such aggressive instability. Known instead by his family for his great kindness and calm, none had ever witnessed the kind of shouting, flailing, accusatory invective he hurled at the two young women – Dr Y and an attendant nurse – when they attempted to introduce a penile catheter to relieve his obstructed, now increasingly distended and painful, bladder.

They hoped their professional patience, kindness and reassurance would rapidly calm him: they did not. They assumed his aggressive barrage was due to impersonal physical determinants – pain, exhaustion and a bloodstream now loaded with opiates and renal failure. 'He will settle now', said Dr Y to the nurse soon after Cyril had been tranquilliser-injected and his catheter secured, 'maybe we'll all, at last, get a good night's sleep'. They both sighed with wearied relief.

Cyril did settle and all did sleep well that night. When Cyril awoke many hours later he seemed utterly transformed: docile, submissive and largely wordless and withdrawn though clearly sentient. But three days later Dr Y’s relief has turned to a new concern. ‘Are you depressed?’, she asks Cyril softly, but Cyril turns his head to gaze away from her and does not answer.

Later that day he sees me passing, alone. His wizened right hand emphatically beckons my attention. By his chairside I carefully avoid his catheter bag and then bend to him slowly and receptively. He reciprocates similar movements and gestures: our convergent leanings are already a rapport.

‘Can I talk to you?’ His tone is confidential and fraternal: I sense this initiative has great risk and importance for him.

My smile is intended to embolden, not just mollify.

‘Look, this has all been very difficult for me…’ Cyril’s voice quakes a little.

I think I know, but fear misattribution. ‘What is?’ It is important I secure a safe foothold.

‘I felt terrible … those young women having to do that … I’m a private person and those are certainly my private parts. I know they’re trying to help me, but I can’t describe to them just how small and pathetic I feel…’

He holds my gaze. ‘You’re very young, too … but you’re a man. I hope you don’t mind me saying such things.’ Cyril pats my hand to reassure us both. Without saying more he trusts that I understand far beyond.

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This brief interchange occurred in the first week of my first job as a doctor. Yet the subtext – of such power, poignancy and meaning – has endured as a sharp and instructive personal memory for decades: yet it was merely one of thousands of similar examples of the centrality of imagination and the implicit in our understanding and exchanges with others. What is such subtext? And are we dealing with it better with the passing decades?

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2. Home. 2010

Forty years later I am reading a novel. Its central character is a man, A, struggling with ageing – his successive losses, retreats, compromises and griefs. In one passage his previously strong and athletic frame missteps to a clumsy, weakened and fracturing fall. Soon after he is mindful of how another quotidian and basic function is failing him: his micturition. This previously brisk, predictable and controllably efficient activity was now anything but: frequently troubled in starting, stopping, controlling or directing. On one occasion he fumbles urgently in his underclothes to find his penis, then gazes at it sorrowfully: *a dead mouse*, he thinks, an organ of loss, failure, sorrowful reticence and shame. His mind reels back to his youth's very different organ: one of potency and possibility, of charismatic and mysterious pleasures, of mutual desires and the generation of new life. But A's organ of pride and pleasure has involuted to one of humiliation and encumbrance: a dead mouse, a source of avoidance, not attraction.

The pathos of these thoughts and experience now crystallise to a dark epiphany: A's urogenital decline is a symptom and metaphor of his life-course and fate. A knows that such is the ineluctable and near-universal price we pay for age. Yet this commonality does not relieve A's gnawing shame: it constantly tugs, distracts and sullies. It is worse still – he must not and cannot talk about it…

Over my decades in medical practice I have seen the many ways that this powerful and poignant paradox gets acted out – yet so rarely talked about by either patients or practitioners. Indeed, this provides an excellent working definition of shame or humiliation: they are states that defy direct expression or exploration. So the state is rarely stated; instead we must infer it.

From what? Well the displacements and defences are common enough: anger, avoidance, agitation, bravado, 'depression', too-brittle alacrity, blame, withdrawal … all of these may conceal and harbour the disturbingly unspeakable. So, to decipher, we must turn to *context*, and for that we must employ *imagination* – a capricious if seminal enterprise and one easily mistimed: like wet soap, if we attempt to grasp the shame or humiliation of another too strongly or rapidly it will certainly slip away, sometimes irretrievably.

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3. Sybil and Sam

January 2017. General Practice.

I have known Sybil nearly forty years. She is two decades older than I, so she is now enduring and struggling in the undrainable swampland of age's losses and compromises: I am gazing towards it, grateful for my vantage point at its margins.

In her middle years Sybil was formidable, attractive and successful in her work, her family and her wide social network. Until her eighties biology had been kind to her, too: she had retained a youthful vitality, autonomy, trimness and wit sufficient to retain her central roles of matriarch, hostess and wise older woman.

But in the last few years such biological benevolence seems to have abandoned Sybil. First she lost her beloved husband and oldest child, then – widowed and alone – her own health: a failing heart, a post-cancer colostomy and a painfully degenerating spine have slowed, weakened and housebound this previously gregarious and independent woman. And her confinement is not even to her own long-cherished home: practicality has necessitated sheltered accommodation.

She is now sitting with me in this new and much-reduced residence.

'I wish I could make you a cup of tea, doctor', she says forlornly, trying to retrieve her erstwhile initiative and hospitality.

'Oh, it doesn't matter … I'm fine' I reply, attempting to be both reassuring and unintrusive.

‘But it matters to *me*! I suppose because I know I’m *not* fine … I’m sorry, I shouldn’t talk like that…’ Her spiked anger fades rapidly into contrition, and then abject candour. ‘But then I’ve known you so many years, doctor, that I think you’ll understand. You see, I hate living like this: my body failing, my marriage and home gone, my reasons for being in this world now largely beyond me … I don’t now even have the resources or the wherewithal to take control of this…’ Sybil’s gaze is direct, desolate yet defiantly spirited. *You know what I mean*, she seems to be saying.

Possibly to relieve my own sense of helplessness as much as hers I tell Sybil I would like to refer her to our psychology service. ‘They can visit you at home. But don’t worry, you won’t lose contact with me. I’ll come and see you again in a fortnight.’

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Sam the psychologist seems quickly to understand my description of Sybil and her plight. ‘We’ll go through our usual procedures to engage her and then decide what to offer her.’ Sam is cheerfully matter-of-fact: I imagine I am talking to a travel agent.

The ‘usual procedures’ consist of a brief telephone call, followed by a long and standardised questionnaire that enquires about the range and severity of Sybil’s symptoms and possible risk factors. Sybil returns this by post.

I promptly receive a formatted email from Sam’s office. It informs me that Sybil’s symptom and risk scores are low. This leads to their procedural care pathway: a short-term low-intensity intervention by an assistant (inexperienced) psychologist. This makes little sense to my understanding and experience of Sybil. What sense does it make to Sybil? I call her.

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Sybil’s voice is welcoming yet weary; she sounds slightly short of breath. I ask her about her preliminary contact with the psychology services: the screening phone conversation and then the questionnaire.

‘Oh. I answered their questions’, she tells me, as if to excuse herself.

‘Well, sort of. But I think there was a lot you *didn’t* say…’ I venture, hoping I have not, already, said too much.

‘What does that mean?’ She sounds stronger in her wariness.

‘Well, they seem to think you’re just a bit down, a bit worried … but we both know that’s too simple and a big understatement…’ This is tough territory; I hope she hears tenderness, too.

‘Yes, but that’s between you and me. I’m not going to have that conversation with anyone else. Particularly if their staff keep changing but keep asking difficult and personal questions. You’ve got to have trust for those kind of conversations, and that takes time … Yes, I’ll talk to you because I know you’ll understand. But no, I don’t want to talk to a series of strangers who don't understand and might have me put away somewhere…'

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Despite Sybil's stoic circumspection I still think she needs help beyond the time and attention I can provide.

I ask to see Sam again, to describe the interlocking predicaments of Sybil and myself.

Sam listens carefully, looking up towards the ceiling and stroking his chin.

'This is tricky. She definitely has low scores, so our suggested care pathway is correct for these. You'll know that our assessments, treatment programmes and outcome studies are now all based on measurements and then statistical analysis and correlation. That's how we assemble a solid *evidence basis* for our treatment packages and then our tendered services. It's important to understand that we need this schematic approach to satisfy commissioners: we can then assure them of the nature and quality of our service, its costs and its likely outcomes…'

I feel I am being lectured and schematised. 'Maybe that looks impressive on a management spreadsheet, but that's not much help to me trying to help Sybil … do you need to design a Shame Questionnaire first?' I hear peevishness in my tone now.

'But we *are* offering help', says Sam, tartly.

‘But it’s not the kind of help she needs.’ I feel flushed with impatience.

‘Why do you think that?’

‘Because of my conversations with Sybil – what she’s told me.’

‘Well, with respect, that’s hearsay. In contrast, we’ve conducted an extensive questionnaire, directly with the patient. That tells us a lot and we can quantify it, too…’

‘But there’s a whole stratum of experiences she won’t tell you about … not yet, or possibly ever.’

‘The problem with that is it’s *you* saying that, not her. Our system can only really work with direct speech and evidence…’

Sam is logical but I am frustrated by his apparent incapacity for the unspoken or irrational. ‘So everything else is deemed an irrelevance or a contamination’, I say.

‘In a way, yes.’ Sam seems pleased to return to this simplicity.

‘But Sam, aren’t there times in your life when you want people to perceive and understand something painful and compromising that you don’t want to, or cannot, verbalise … to respond to the *implicit*?’

Sam looks away and shifts in his chair. ‘Well maybe … I don’t know … but this is work, it’s different…’ Sam’s voice fades into equivocation.

He clears his throat to continue. ‘Look, we’ve got lots of patients to see, targets to meet, commissioners to satisfy. Amidst all this I want our service to survive. These procedures we have – to assess and treat people – are the best ways we have to achieve all that.’

As he talks of ‘the service’ I notice how purposeful and strong Sam’s voice becomes.

That is one example of how to deal with shame, I think.

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A man is hid under his tongue

– Ali Ibn-Ali-Tabib (7th century), *Sentences*

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