Point of Care Foundation

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ESSAY

Humanising medical care after the pandemic

We should hang on to the freshly gained insights into the fundamental importance of enabling human connections—between patients, families, and staff—and put them to practical use, writes **Jocelyn Cornwell**

Jocelyn Cornwell *founder and former chief executive*

Rage and despair about the NHS spurred me to start a charity called the Point of Care Foundation in 2006. Its mission is to “humanise medicine.” Just over a year ago, I left my position as its chief executive, and now, as the NHS rebuilds and reshapes its services after the pandemic, I find myself reflecting on how far there is to go to fulfil the foundation’s mission.

I was galvanised to set up the foundation by harrowing personal experience. In the autumn of 2005, I took a call from my sister. She had given birth overnight, and the baby was now in intensive care. She did not know what had happened or why, but she did know it was “something terrible.”

Later the same day she discovered that her baby son, C, had suffered oxygen deprivation during birth. The labour ward staff were seemingly unaware of his plight for far too long, and when they did notice, they failed to respond appropriately. C had been resuscitated on the labour ward before being transferred to the neonatal intensive care unit, where he stayed for many weeks.

Today, C is 15 and has an extraordinary spirit. He is brave, determined, and stoical, but he is unable to speak and will never be able to live independently. The harm he suffered was completely avoidable, and it changed his life, as well as the lives of his parents and siblings.

For me, the inhumane way that hospital senior staff acted towards his parents made the trauma even more unbearable. Immediately after he was born, his parents were left completely in the dark. He was not their first baby, but they had no idea he was in trouble until they saw staff in the labour room panic.

In the neonatal intensive care unit, C was put in a cot in a single room, which was baffling. All the other babies were tiny or had visible deficits, but there was nothing remarkable about his size or appearance. Why was he in the only single room? Gradually, it dawned on us that the staff were keen to prevent his parents from chatting to other parents. Staff members’ body language was always awkward—no one would look the parents in the eyes and senior people avoided them.

In the months that followed, the NHS trust investigated the “incident,” as they termed it (a choice example of bureaucratic language) without telling his parents. When the family finally forced the trust to participate in an investigation by outside experts, the trust broke its own promises to keep in

touch, involve the parents, and keep the channels for communication open. When C was almost a year old, my sister heard from a neighbour that the midwife on duty the day he was born had been suspended and had not returned to work. C still goes back to the hospital when he needs medical treatment, which is often. The trust eventually, many years later, admitted negligence in court, but no one from the trust has ever apologised or reached out to his parents.

Foundation

In 2006 I wrote a bid to fund a programme of action and research that would aim to “achieve patient centred care in practice . . . and enable initially some, gradually all, NHS services to design and implement organisational systems and processes capable of protecting patients from depersonalisation and providing care that is truly centred on the patient.” The Point of Care programme would try to prevent or reduce suffering in healthcare that can be avoided: the everyday occurrences, minor insults, failure to follow best practice, inadequate communication, lack of information, lack of empathy, dehumanising routines, and insensitive behaviours that diminish patients as people.

The King’s Fund supported the programme generously from 2006 to 2013, after which we established the Point of Care Foundation as an independent entity. Now in its eighth year, the foundation runs two main programmes.

The first, the Sweeney programme, teaches healthcare staff to step out of their role; observe their own service; gather intelligence about the service from patients, families, and colleagues; and use it to improve the experience of care, often in collaboration with patients.

The second is Schwartz rounds—communal reflective practice in the form of regular, monthly, hour long meetings, open to all staff.¹ They offer a facilitated process and a psychologically safe environment in which to reflect together on the social and emotional aspects of their work with patients. The Point of Care Foundation helps organisations establish their own regular schedule of Schwartz rounds and trains the facilitators.

The Sweeney programme is ostensibly about patients, and Schwartz rounds are for staff only, but both approaches use stories and storytelling to help staff to connect with themselves, their own humanity, and

patients. The fundamental premise behind both is that the work of humanising medicine should be ongoing and continuous. It does not have a beginning and an end: it is an aspiration, an ideal, and a goal, always in need of renewal, which requires constant attention because the human connection between health professionals (by which I mean everyone employed in healthcare) and patients is fragile, under constant threat, and easily undermined.

The forces that undermine human connections are systemic: they change over time and vary in different contexts and settings, but they shape the way staff feel and behave towards patients and each other.

The challenge of covid-19

Last year, as I came to the end of my time leading the Point of Care Foundation, I had another personal encounter.

During the pandemic, my niece spent six weeks in hospital, starting in week 24 of her pregnancy. She was admitted for observation in a state of great anxiety because she had bleeding on and off throughout her pregnancy that was becoming heavier and more frequent. Months later, she is now at home with her healthy baby daughter, but at that point, there was no way of knowing the outcome.

She bled every day of the six weeks she spent in hospital. Every day she was moved down to the labour ward and then back when the bleeding stopped. Every time she returned to the ward in which she had been staying, she found her belongings bundled into a black plastic bag and moved to a new bed.

For five of the six weeks, she was on a postnatal ward, surrounded by women who had already had their babies and whose partners were allowed to visit, but her husband, apparently because her baby was not yet born, was not allowed to visit because of covid-19 restrictions.

Throughout her time in hospital, what caused the most stress was the lack of continuity in her care and the lack of continuity in the communication about her care. Every day, the consultant responsible for her (and perhaps in charge of the whole ward) changed. Every day, the new doctor would devise a new plan of care, without speaking to her, and then announce the new plan without referring to the previous one.

After a few days, my niece told a doctor that she found the frequent changes frightening. She was told that from then on, she would have a named consultant. In practice, however, nothing changed, and the daily changes in care plans continued. Isolated and alone, missing her husband and 18 month old son, she was extremely frightened and anxious about her own safety and that of her baby.

Failure to make progress in humanising care

When I reflect on my niece's story, I do not doubt that staff were doing their best under circumstances that were incredibly difficult because of covid-19. I can imagine that they might have been short staffed, but I wonder how the doctors and midwives rated the service? Who did they think was in charge? Were they aware of the frequent changes in patients' care plans? If so, what did they think about them? If any staff members, including the more junior staff who spent the most time with the patients, had concerns about a patient's wellbeing or how she was coping, what could they do about it? What was communication like within the team?

I do not doubt their intentions were good. The midwives told my niece that, if it was up to them, her husband would be allowed to visit, and they rolled their eyes when they told her that "infection

control" would not permit it. A consultant was visibly angry on finding my niece's most recent plan of care had again been altered, muttered about her colleagues under her breath, and promptly changed the plan back again. But the fact is that, for the patient, nothing changed. Her suffering went on.

My niece's story is not unusual, nor is it specific to maternity services. Over the years, the Point of Care Foundation has heard countless examples from child and adult services in acute, mental health, and community settings of patients being left to worry that they have been forgotten because no one tells them what is happening. Of patients in pain and unable to attract the attention of a member of staff, of losing trust as a result of being told one thing one day and a different thing the next, not because their condition has changed, but because of a change in personnel. Of being given bad news in front of strangers, being told a life changing diagnosis as a casual afterthought, or having to comply with a rule for which there is no reasonable justification. And not knowing, and not being able to find out, who is responsible for their care or how to speak to that person.

It does not have to be like this

If preventing patients from avoidable suffering was a priority for the NHS it would take relatively small but important changes in practice to produce much better outcomes.

On admission to hospital or a new service, patients could be encouraged to speak about worries or concerns to any member of staff. Perhaps patients should always be given the name of the person in overall charge of the service and the name of a person responsible for their care. Clinicians would know that changing care plans without reference to a previous plan might cause anxiety and would agree to keep changes to a minimum and always involve patients with capacity in discussions about changes. Clinicians would also be concerned that multiple changes in the care team might undermine patients' confidence and trust and would take action to mitigate the risk. They might, for example, offer the patient a named person to go to with their worries or ensure that a senior clinician speaks to the patient about the changes.

I would like to see the inconsistent treatment of visitors on the same ward eradicated and continuity of care prioritised. The lines of medical authority and responsibility for individual patients would be clear, and staff would be familiar with how their patients experience the service because they would receive feedback regularly; some of them would periodically listen to patients' stories and report back.

Covid-19 has reminded us of the importance of human connections and how much we—patients, families, and staff—need to feel that the person as well as the patient is cared for. Over the course of this pandemic, two things have struck me forcibly: the stories about families with patients in intensive care doing their utmost, through photos, pictures, and sound recordings, to ensure that staff had a sense of the patient as a person; and the stories about the distress felt by staff about not being able to comfort and protect patients from feeling abandoned and alone.

Covid-19 was a new experience—a widespread and dangerous illness with, at the beginning, no effective treatments, which stripped away the humanity of care in ways that were all too clear. Healthcare staff in full personal protective equipment had a dehumanising impact on patient interactions; patients and families were separated and denied access to each other; patients suffered and died on their own; staff were left feeling impotent, exhausted, and frightened. The public response to healthcare workers during the crisis showed

an overwhelming appreciation for the fact that carers are human too. The pandemic revealed, on a scale not seen before, the centrality of the human experience of care—for patients and professionals.

As we emerge from the pandemic, the biggest problem facing the healthcare system is going to be retaining an exhausted staff and attracting new people. What makes healthcare special—for those who work in it and those who rely on it—is that it is a profession about caring for your fellow human beings. Historically, we have not done enough to make human care a reality across the health system. As we look to put this tragic year behind us, we should hang on to the freshly gained insights into the fundamental importance of enabling human connections—between patients, families, and staff—and put them to practical use.

Biography

Jocelyn Cornwell is the founder of the Point of Care Foundation, an independent non-profit organisation that works to make healthcare more human, for patients and staff. She originally trained as a medical sociologist and spent her career working in and around the NHS, as a locality manager, a senior civil servant in the Department of Health and Social Care and in regulation, first at the Audit Commission, and later at the Commission for Health Improvement. She is a trustee of Action for Medical Accidents.

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