Improving patient safety by shifting power from health professionals to patients

Patients and carers are key partners in the quest to make care safer, argues Tessa Richards

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The UK government’s commitment to implement “Martha’s rule,” is good news for patients. It will give patients and their families an explicit right to request a second opinion if a patient’s health condition is getting worse and they feel their concerns are not being taken seriously. A similar rule, called Ryan’s rule, introduced in Queensland, Australia in 2013 was spurred by the activism of the parents of a three year old boy who, as in Martha’s case, died a preventable death. It’s been widely evoked, reported to have saved lives, and adopted in other states. Both rules are testimony to the determination, persistence, and skill of patient advocates to drive policy change to make care safer in the wake of personal tragedy.

Martha was 13 when she died two years ago from septic shock. In a profoundly moving 22 minute interview on Radio 4’s Today programme (broadcast on 4 September) Merope Mills, Martha’s mother, describes Martha’s last gruelling weeks on the paediatric ward of a London hospital. During this time, she and her husband kept constant vigil at her bedside and closely observed how and by whom care was delivered. The agony of loss is evident in every word as Merope Mills recounts what they experienced and felt over this time. How they repeatedly questioned the health professionals looking after Martha, and how their concerns about her deteriorating condition were brushed off and belittled by them.

Merope Mills’ insight into health systems weaknesses is forensic in its detail. She points to flaws that many patients will recognise well. An overly hierarchical structure, lack of continuity of care, inadequately trained staff, unwillingness to acknowledge mistakes, and a failure to listen to patient and family concerns. She cites the power imbalance between health professionals and patients as the major factor behind unsafe care. And cogently argues how they and their carers should be given full and timely information about the medical situation they face and more agency to challenge health professionals. Her interview should be compulsory listening for doctors, nurses, and medical students alike.

All patients are familiar with the power imbalance when they encounter health professionals. In a non acute setting preparing your agenda and questions in advance can help counter it a bit. But once you are horizontal in a hospital bed, as Mills observes, you are soon rendered powerless.

My experience of this powerlessness and inability to get staff to understand or listen to my concerns during time spent in intensive care and high dependency wards still haunt me, even though my overall care and outcomes were good. On two occasions second opinions pulled me back from the brink.

On the first, a visiting medical friend, concerned about my condition, challenged and succeeded in changing my management. On the second, a family member helped me obtain a second opinion overnight via whatsapp. The information I obtained gave me the courage to question my consultant’s decision to undergo a risky procedure and jointly we agreed not to proceed.

Co-design should be King in patient safety initiatives

Health systems have long paid lip service to patients and carers being experts by experience and emphasising the importance of health professionals listening to their views and taking their concerns seriously. Actively co-designing research and policy on patient safety with patients and carers is now widely seen as best practice. But there is a long way to go on all fronts.

The theme of this year’s World Patient Safety Day (17 September), a day set up by the World Health Organisation five years ago, was “Engaging Patients for Patient Safety.” Why and how this should be done was discussed at a recent webinar, co-designed by patients, held by Imperial College London and Imperial College Healthcare NHS Trust. Henrietta Hughes, patient safety commissioner of England, who is responsible for implementing Martha’s rule in NHS hospitals, spoke with passion about the unacceptably high level of avoidable harm to patients and raised the question “Are we normalised to harm?”

She went on to repeat Merope Mills’ message about the imperative of tackling the power imbalance between patients and health professionals, valuing their views more, and the need for greater transparency.

“There is no place for a fortress mentality and cover up,” she said. Nor for regarding “patient and carers views as worth less (or even worthless) than health professionals.”

In 2019, NHS England launched a new framework setting out how NHS organisations should involve patients in patient safety. A key plank is to appoint Patient Safety Partners. Ensuring these include people who can speak up for disadvantaged communities, is widely seen as important for they bear a disproportionate level of harm from healthcare. But as Hughes underlined, many NHS organisations have...
not yet appointed them, and it is not clear how their work will be monitored and evaluated.

At a second webinar held to mark World Patient Safety Day led by the Patient Safety Learning hub, emphasis was put on patient and carers being involved at strategic level within hospitals. NICE guidance supports the appointment of paid patient directors in NHS Trust, but there are still only two in position.

At a global level, WHO’s Patients for Patient Safety network has been pushing the envelope on patient and carer involvement in the quality and safety of care for a decade. Many of its members have taken to advocacy after being harmed by healthcare. The network’s recently retired co-chair, Helen Haskell, has been outspoken in her criticism of the culture of healthcare.

Turning healthcare into what Henrietta Hughes referred to as a “high safety business,” won’t be easy. She and newly appointed patient safety partners, and those who work with them, face many challenges in the overstretched NHS. The same holds true, of course, for all countries health systems. A welcome global commitment to step up action to improve safety set out in WHO’s Global Patient Safety Action Plan 2021 - 2030 includes detailed objectives for strengthening patient involvement. Its first report of progress with reaching its objectives was presented at this year’s World Health Assembly.

But there is surely also a case for much wider involvement of patients and carers in promoting safety? Health services routinely request feedback from patients. We get bombarded with messages such as “Tell us how we did today,” “Would you recommend this hospital to others?” “How would you rate your experience?” Why not specifically ask “How did you feel about the safety and quality of the care you received from us? Do you have views on how it could be improved?”

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