EDUCATION AND TRAINING

An audible patient voice: How can we ensure that patients are treated as partners in their own safety?

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How can patients and their relatives make their concerns heard by healthcare professionals? Many serious adverse events are preceded by patients’ worry and concern. This article explores changes in the structures and processes of healthcare that might facilitate safer systems. One important tool might be the ability of patients to become equal partners in the recording of their clinical history.

KEYWORDS: patient centred, patient safety, adverse event

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The experience of not being heard

Dr Saleyha Ahsan is a doctor working in emergency medicine. She experienced the powerlessness of being a relative when her mother was admitted to hospital. Despite being a doctor (and an articulate renowned broadcast journalist), her concerns about the dramatic deterioration of her mother went unheard.

Alison Phillips suffered serious injuries as part of a road traffic accident. On several occasions during her hospital stay, she and those close to her identified serious problems (that resulted in prolonged intensive care stays) well before her clinical team had.

Lowri Smith has a complex congenital heart condition and has been under close supervision by a tertiary centre for her entire life. In 2018, she identified an infected central line but had difficulties to gain support with getting it removed (Box 1).

What is common to all these experiences (and many others) is that patients and those close to them had prior experience and were applying their learning but had great difficulties to be heard as equitable partners in clinical safety during episodes of serious illness, and this despite being able to articulate this knowledge. Clinicians dismissed their evidence and expertise and were able to do so effortlessly.

Quality improvement beyond co-production

The reasons behind the observations earlier are complex and are sometimes described with the term ‘culture’. Culture manifests itself in beliefs and behaviour: beliefs about what is right, acceptable, tolerable and that are difficult to observe and quantify; and behaviours that can be observed and quantified.

The usual response to ‘cultural’ challenges, complaints or adverse events are educational interventions. It would seem that after decades of a focus on better communication, ‘what matters to you’, co-production and shared decision making, something more transformational might be required? That would be something that shifts the balance of available information, intervention and governance (and power) towards those that are affected by medical error and adverse events.

A narrowing gap between professionals and patients

In many industries, customers have gained access to tools to that were previously the prerogative of experts, from reading of gas meters to building furniture. This has enabled a shift in the relationship between customers and experts. In medical care, cautious signs of such a shift are visible: using vital sign monitors during the COVID-19 pandemic, checklists for safer surgery, and accessing clinical records to document their own symptoms and views.

A rising number of patients with chronic healthcare conditions in the UK are mastering the self-administration of complex and time sensitive medication at home while being wary that they are denied the ability to exercise this task in hospital. In all these instances, the gap between patients and healthcare professionals is narrowing.

An audible and readable patient voice

Taking a history is another pivotal step in the clinical process, for medical emergencies presenting to hospital, an extended history taking is often warranted. Against the backdrop of rising numbers of emergency visits, in recent years there has been
Box 1. Lowri Smith’s experience

In 2018, I was a patient in the intensive care unit (ICU). At the
time, it was a precautionary measure following a lengthy and
complex cardiac procedure via the jugular vein. I was an ICU
patient for 5 days and intubated for 1–2 days. I had a central
line place in my neck delivering antibiotics and other important
medication. I have a horrific history of infection having had
sepsis, which travelled to my heart resulting in endocarditis. The
endocarditis destroyed my mitral valve; as a result, I’m always
cautious of possible infection.

After 3–4 days in the ICU, I noticed that the central line felt
warm, a sure sign of an infection brewing. I was immediately
suspicious and mentioned it to my nurse. She stated that, as it
was a ‘bank holiday’, the best she could do was swab the site,
send it to the lab and wait 2–3 days for a result. I wasn’t happy
with her response but let her take a swab. What she didn’t
know is that I never give up that easily even when I’m lying in
a hospital bed. Waiting 2–3 days means any infection would be
circulating in my bloodstream by then.

There was another nurse, who I had observed for some time,
caring for the patient opposite me. She appeared to be very
experienced. Her patient was receiving extra-corporeal membrane
oxygenation, and the nurse was constantly talking with her
patient. I managed to get her attention; I explained my
concerns over the central line, possible infection and my very
real history of septic shock and endocarditis. After examining
the site, she agreed with my observation and alerted a nearby
anaesthetist. The central line was immediately removed; and
the anaesthetist inserted a canula into my hand because I still
needed intravenous medications. Had they waited 2–3 days,
they could potentially have been dealing with something far
more serious. We all know that prevention is always better than
cure. I don’t know why my own nurse was reluctant to take the
necessary action.

Regardless of your level of experience, please don’t dismiss a
patient’s concern. Patients with long-term health conditions are
often experts in their own conditions. They have picked up a lot
of knowledge during their patient journey and their instincts
are often spot on. They will be able to tell you what is normal
for them and provide a good history. Their ‘normal’ won’t
necessarily reflect what’s in the textbook, and that’s okay. When
a patient raises a concern, please take it seriously and, if needed,
seek the opinion of their specialist team. Due to my medical
history and cardiac condition, my risk of infection is high, and the
potential consequences could, according to my specialist team,
easily be fatal. The source of my sepsis (in 2003) was never
established and could literally have been ‘picked up’ anywhere.
When you are ill and in receipt of copious amounts of sedatives
and other strong drugs, it takes an enormous amount of effort
to do even the smallest thing, including stringing together a
sentence. It is a time when even the most confident person is
very vulnerable. You should not have to think about advocating
for your own safety as a patient.

Allergies, systematic history, risk factors etc.)12,13 Another team
in Toronto was able to identify ambulatory patients significantly
quicker than the routine nurse-initiated patient identification
using a self-check-in kiosk.14 Automated tools have also been
shown to reduce the waiting time before seeing a healthcare
professional in the emergency department.15 A group in Sweden is
currently investigating the use of a self-reported history taking for
patients with acute chest pain collecting data to assess chest pain
according to the HEART score.16

Self-reported history taking tools could aid a shift in the
relationships between healthcare professionals and patients and
an increase in the time for direct patient contact, thoughtful
communication and subsequently improved patient care.
Implementation at scale in large systems and over long periods
of time might be required to explore the real effects for patients and
the safety of their care.

In this edition of the Future Healthcare Journal, readers will find
examples on how more reliable safe care might be practically
achieved by and with patients during major surgery, critical
deterioration or even routine care. The impact of the described
interventions has often not been evaluated at scale yet, but
the philosophy and practice are aligned with a vision or modern
healthcare where patients and those close to them are equitable
partners with their clinicians, with the ability to change the course
of their care in real time.

Whether these tools allow true listening to patients and those
close to them, and change some of the culture and hierarchical
thinking that has dominated medical care and hindered
breakthroughs for patients’ safety, remains to be seen.

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