BMJ 2019;366:l5565 doi: 10.1136/bmj.l5565 (Published 17 September 2019)

FEATURE

ESSAY

Unleash the power of patients to make care safer around the world: an essay by Helen Haskell

Involvement in medical care by patients and the public could move the global patient safety programme out of the doldrums, says **Helen Haskell**

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This week the World Health Organization launches a new global initiative aimed at making healthcare safer and reducing medical error. By designating 17 September as annual World Patient Safety Day, WHO seeks to raise awareness of the deaths and disabilities that result from medical error and increase uptake of its many recommendations for achieving safer care.[1] The day will be marked by eye catching events including turning Lake Geneva's Jet d'Eau and monuments such as the pyramids of Giza orange for the day, urging people to post comments and questions to the hashtag #WorldPatientSafetyDay, and showcasing a variety of conferences, media campaigns, and other events.

For me, as co-chair of the WHO Patients for Patient Safety Advisory Group, this is a welcome step. Like many patient safety advocates, I came to this mission from the loss of a family member—in my case, my 15 year old son Lewis, who died from the effects of a medication error following elective surgery. In the years since Lewis's death, I have worked to advocate for drug safety, infection control, hospital rapid response, medical education, and patient-provider communication, all of which—or the lack of which—played a role in his death.

As I have talked to other injured patients and families, I've noticed patterns of harm that are strikingly similar around the world. In spite of gains in knowledge, these patterns have remained substantially unchanged, and largely undiminished, over time. WHO's recharged sense of urgency provides badly needed support for the global patient safety movement.

The scale of medical harm

The adoption of World Patient Safety Day arises from a call to action to this year's World Health Assembly from WHO director general Tedros Adhanom Ghebreyesus.[2] The director general's report affirmed findings that patient safety efforts have largely failed to move the needle on reducing harm, even in high income countries where active steps have been taken. In low and middle income countries, many fundamental safety measures have yet to be adopted or adapted to low resource settings, where basics needs such as clean water and reliable electricity may be lacking. Patient harm from adverse events remains one of the top 10 causes of death and disability in the world.

Recent studies indicate that medical treatment causes harm to about 1 in 20 patients globally, exceeding death from diseases such as malaria and tuberculosis in parts of the world where those diseases are endemic.[3,4] A 2018 study in the *Lancet* showed that low value medical care poses more risk to people in low and middle income countries than does a lack of access to medical treatment, at a cost of five million excess deaths a year.[5]

The World Health Assembly resolution declares patient safety a global priority and contains more than two dozen recommendations. Among these is a specific recommendation to learn from patient harm and patient safety risks by establishing reporting, learning, and feedback systems that incorporate the perspectives of patients and families.

Other recommendations urge member states to work with patient organisations and other stakeholders to "promote, prioritise, and embed patient safety in all health policies and strategies" and to put in place systems—including capacity building initiatives, networks, and associations, and the use of patients' experience of care to build safety and harm minimisation strategies, as well as compensation schemes, into all aspects of healthcare—for the engagement and empowerment of patients' families and communities (especially those who have been affected by adverse events) in the delivery of safer healthcare.[6]

This attention to topics that have been patient priorities for years is an indication that policy makers are coming to suspect what patient advocates have long believed: that patient and public involvement is the missing ingredient that has the potential to move the global patient safety programme out of the doldrums.

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Patient engagement in patient safety

Patient and public involvement—patient engagement—in patient safety is in some ways a complex phenomenon. It is intuitive that giving patients and families a greater say in their own decisions, letting them serve as an extra pair of eyes, giving them information so they can manage their own treatment and know when things are going wrong, and soliciting their feedback and assistance when things do go wrong all provide for greater safety. The same goes for community involvement in healthcare and patient involvement in research.

At the same time, however, evidence is thin. These are not practices that lend themselves to randomised control trials, partly because they are so sporadically taken up. Patient engagement practices are consequently often promulgated out of the sense that they are the ethical thing to do. In addition, harmed patients and families overwhelmingly feel that the harm would not have happened, or could have been mitigated, if their voices had been heeded. In this sense, patient engagement cannot easily be disentangled from patient safety.[7]

To name just two of the measures whose dissemination could be enabled by the WHA resolution, reporting and analysis of adverse events have been a mainstay of patient safety systems for years. And patients and families, as the only people who traverse the entire medical system, can, and if given the opportunity often do, report safety problems that providers do not.[8 9] The inclusion of the patient perspective in reporting systems is a relatively new phenomenon, however, and has not yet been standardised.

Event reviews, or analyses of the root causes of adverse events, are also a standard part of safety process adapted from other high risk industries. Interviewing patients and families and the involvement of patient representatives are an important part of this process.[10-12] Yet actual inclusion of patients is vanishingly rare. It is to be hoped that the encouragement of WHO will change practice in these and other areas. Overall, the assumption in the WHA document is that patient and public involvement will provide a balance that will make care safer across the board, a belief that is in line with WHO's emphasis elsewhere on patient engagement and people centred care.[13]

Patients for Patient Safety

Patients have been part of the WHO campaign for patient safety since 2005, when a network of "champions" known as Patients for Patient Safety (PFPS) was created as part of the World Alliance for Patient Safety.[14] From an original group of 20 activists, PFPS has grown into a loosely constructed network of over 400 advocates scattered across the world. PFPS champions volunteer on WHO projects and collaborate with WHO and other international organisations on patient safety events in their countries and regions. Many are community activists working to improve healthcare safety and quality from outside, a role that can be lonely and discouraging. For these patient advocates, PFPS can facilitate connections that might not otherwise have taken place. While PFPS champions act as independent operators, many have achieved remarkable success in raising the profile of patient safety matters in their own countries.

An example of this kind of independent action is Evangelina Vazquez Curiel, a young Mexican mother who became a PFPS champion after her son was neurologically damaged by kernicterus, or infant jaundice, an avoidable condition that causes cerebral palsy if left untreated. In the 14 years since she joined PFPS, Vazquez Curiel has become a regional force in patient safety, with leadership roles in both Mexican and Latin American PFPS networks and close collaboration with local healthcare institutions. She is now producing online patient safety courses for Spanish speaking patients and healthcare providers.[15]

Nagwa Metwally, another active champion, has worked for years with the hospitals at Ain Shams, one of Egypt's oldest medical schools. Metwally began by organising volunteers to do weekly "walkarounds" in the women's hospital to find matters that needed attention. This gradually evolved into a relationship in which she also helped find donors for needed equipment, and ultimately for a new geriatric hospital. The culture at the university hospitals has changed; staff wear name tags, nurses attend training sessions, and the medical school has a patient safety curriculum. Metwally is now on the hospital's board. The main building at Ain Shams will be lit up orange this 17 September.[16]

Moving forward

It is largely because of the efforts of activists like these that patient engagement has finally moved to the forefront of the patient safety agenda. Yet around the globe there are many more patient advocates who are thwarted by a lack of recognition and funding. More support and encouragement for patient advocates is needed, especially in low and middle income countries. If patients are to be empowered in the ways the WHA lays out, it will involve community education and involvement. These are demanding undertakings requiring skill, organisation, and government support.

And yet, the fundamentals of patient safety do not have to be so difficult. As any patient advocate will tell you, one of the most important safety measures is mutual respect between patients, carers, and health professionals. At its basis, healthcare is an interaction between two people whose goal should be to listen, learn, and try to help each other. That is an area where healthcare has fallen short, for many reasons, with serious consequences for safety. If we want to make it right, that is the point at which we can all begin.

Provenance and peer review: Commissioned; not externally peer reviewed.

Competing interests: Helen Haskell is co-chair of the WHO Patients for Patient Safety Advisory Group, a volunteer committee drawn from the roster of WHO Patients for Patient Safety champions. She receives no funding from WHO aside from occasional reimbursement of travel expenses.

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