Comment

Journal of Patient Safety and Risk Management
2018, Vol. 23(4) 139–141

DOI: 10.1177/2516043518791051
journals.sagepub.com/home/cri


The role of the patient in patient safety: What can we learn from healthcare's history?

Ian Leistikow[1,2] and Frank Huisman[3]

Abstract

Many nations, healthcare organizations and interest groups are addressing the question of how patients can best be involved in designing and executing patient safety policy. Looking back at how patient engagement has developed in healthcare, we can draw lessons on how to engage patients in patient safety.

Keywords

Patient safety, patient engagement, history

Many nations, healthcare organizations and interest groups are currently struggling with the question how patients can best be involved in designing and executing patient safety policies.

To give just one example: in 2013, the British Health Foundation, an independent charity committed to bringing about better health and healthcare for people in the UK, published the results of its research into this question. It concluded that strategies to involve patients may need to concentrate on ensuring that professionals have positive attitudes, are supportive and ask patients for input and feedback; that the infrastructure is in place to do something about patients' comments; and that patients feel able and encouraged to take part in the decision-making process. The report concludes that "greater patient involvement may require changing the culture of healthcare so that patients and professionals are working as partners in a joint team."[1] The report of the Health Foundation may be seen as a late echo of a debate that started in the late 1960s. What has been accomplished since, and why is a similar programmatic call for patient's involvement still imperative?

In 1969, the Dutch neurologist Jan Hendrik van den Berg published a book called "Medical power and medical ethics."[2] The book, which was to see many editions and was translated into English, created a splash in Dutch society. It incited a debate on the technological imperative in medicine and on the asymmetrical relationship between doctor and patient. In the end, this debate led to a wave of legislation meant to "empower" the patient. Van den Berg wrote that patients were hardly ever informed about the interventions a treating physician was planning. "No patient is expected to judge what is best for his body, that judgment now lies solely with the doctor." Van den Berg appealed for more openness and honesty towards the patient and even suggested that patients should be involved in the decision-making process of a therapeutic intervention. If, for example, an X-ray suggested that a patient was suffering from lung cancer, the doctor should show the X-ray when a patient requested to see it. Van den Berg even hypothesized: "I can see it happening that the patient can freely browse through his own patient record."

[1]Dutch Health and Youth Care Inspectorate, Ministry of Health, Welfare & Sports, Hague, Netherlands
[2]Erasmus School of Health Policy & Management, Erasmus University Rotterdam, Rotterdam, Netherlands
[3]Medical Humanities Department, University Medical Center Utrecht, Utrecht, Netherlands

Corresponding author:
Ian Leistikow, Erasmus Universiteit Rotterdam, Burg Oudlaan 50, Rotterdam 3000 DR, Netherlands.
Email: ip.leistikow@igj.nl

The book by Van den Berg can be said to be representative of what medical historian Edward Shorter has labeled the "postmodern era" in the doctor–patient relationship. In a book called *Bedside manners*, he argued that the quality of the doctor–patient relationship is dependent on the levels of science and technology.[3] In the "traditional era" (before approximately 1880), doctors were relatively powerless in terms of diagnosis and therapeutics. In this context, the patient narrative was key. During the anamnesis (literally: memory), the patient shared everything and anything that he thought could help the doctor in making a diagnosis and a prognosis. They were more or less negotiating about it, and it was very common for a patient to ask for a second or even a third opinion. Over the course of the 19th century, medicine gained in diagnostic power. The development of the stethoscope, the clinical use of the thermometer, many forms of endoscopy, and the introduction of X-rays led to a far more superior understanding of disease than ever before. And even though in the "modern era" (1880–1950) the doctor was still relatively powerless in terms of therapeutics, patients came to respect the doctor more than they had ever done before. The aura of "science" surrounding the doctor led patients to trust him in unprecedented ways. From the 1950s onwards, medicine witnessed many breakthroughs in the field of therapeutics (ranging from antibiotics to chlorpromazine, the iron lung and organ transplantation), ushering in what Shorter coined the "postmodern era" (after the 1950s). The doctor–patient relationship was facing a paradoxical situation. Whereas on the one hand medicine had become more powerful than ever, on the other hand, doctors could do without the input of patients to come to a diagnosis and a therapy. In a sense, the patient had been reduced to his disease and his lab values. Increasingly, this led to criticism on behalf of the patient, who was complaining to be "dehumanized." But it also led to self-criticism on behalf of doctors, who increasingly felt that they could not do without the contextual information and the corrective value of patient narratives. In the end, the patient movement successfully called for legislation meant to "emancipate" and "empower" the patient.

So 50 years ago, doctors did not inform the patient about his or her ailment. We have come a long way since. First we started telling patients what their diagnosis was and what treatments were available. Then we started telling them about possible side effects of treatment. Next, we realized that we needed to actually train physicians in conveying bad news. Then we bashfully began to be forthright to patients when our treatment did not have the expected results. And finally, we formalized our openness into procedures of "informed consent" and matured further into "shared decision making." We have come to realize that we should shift our focus from the question "what is the matter?" to "what matters to you?," as the U.S. based Institute of Healthcare Improvement's former CEO Maureen Bisognano urges.[4] These are all profound changes in the culture of healthcare. Now let's take the same journey through the past years in patient safety.

In the 1990s, not a single minute of medical training was spent on patient safety. Students were not told that as physicians, they could and would make mistakes that would harm patients, let alone be trained how to address this when it occurred. Crudely stated, the medical profession was only open to patients about adverse events when there was no way to deny or avoid it. In this respect, it is telling that the word for patient safety ("patiëntveiligheid" in Dutch) was not part of our vocabulary until 2003. In 2004, Dutch hospitals started testing root cause analysis (RCA) for investigating serious adverse events. Before that time, we just asked around informally, and mostly concluded that the involved healthcare personnel should pay better attention next time. More often than not, there were discussions on the issue whether or not to share an RCA report with the patient or his family involved. Most of the time, the policy of the hospital board would be "Absolutely not." An RCA report was meant to serve internal quality improvement only; the patient had nothing to do with it. Around 2005, the first author was involved in organizing the first training of a small group of Dutch physicians in how to inform a patient that a serious adverse event had occurred. It was an eye-opener to them. Today, in 2018, all Dutch hospitals have teams trained in RCA or a similar method; and the outcome of adverse event analysis is shared with the patient involved. Since 2014, the Dutch healthcare inspectorate has mandated that hospitals should involve patients and their family in the investigation of serious adverse events.

So 25 years ago, we did not even realize that patient safety could be an issue. About 15 years ago, awareness of the problem began to develop.[5] We started looking for the causes using methods like RCA. Then we realized that we needed to actually train physicians in communicating this "new form" of bad news to the patient. Next, we decided to inform patients when our healthcare process had failed and harmed them. Only recently have we begun to involve patients in patient safety. For an increasing number of nations, it is now more common to involve patients or their family in adverse event investigations. In the Netherlands, for example, this has been mandated by law since 2016.[6] Patients are also increasingly engaged in patient safety policies, for example through the World Health Organization's initiative "Patients for Patient Safety."[7]

In conclusion, we need to change the culture of healthcare if we really want patients to play a role in patient safety. And we believe, as many do, that patients' active participation will take the quality and safety of healthcare to a new level. Notwithstanding the importance of further improvement, it is useful to realize how much patient engagement in patient safety has already evolved in a surprisingly short time. There is clearly both will and momentum. Over the past 50 years, much experience has been developed on including patients in their own healthcare and we should use this experience to further engage patients in patient safety. What we need is "reflexive professionalism": keeping our professional standards, but at the same time bearing in mind that the interests of the patient and the goals of medicine develop over time.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

References

1. Health Foundation. *Evidence scan. Involving patients in patient safety*. London: January 2013.
2. van den Berg JH. *Medische macht en medische ethiek*. [Dutch]. Nijkerk: Callenbach, 1969.
3. Shorter E. *Bedside manners. The troubled history of doctors and patients*. New York: Simon and Schuster, 1985.
4. Barry MJ and Edgman-Levitan S. Shared decision making – the pinnacle of patient-centered care. *N Engl J Med* 2012; 366: 780–781.
5. Kohn LT, Corrigan JM and Donaldson MS (eds) *To err is human: building a safer health system*. Washington, DC: National Academy Press, 2000.
6. Uitvoeringsbesluit Wet kwaliteit klachten en geschillen zorg [Quality, complaints and disputes in healthcare act], paragraaf 8.7.[Dutch]
7. World Health Organization. *Patients for patient safety. Partnerships for safer health care*. Geneva: WHO, 2013.