

Commentary

For the Many, Not the Few: Patient Empowerment

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Abstract

Today's patients are more knowledgeable than ever before and should be placed at the centre of their own healthcare decisions. Empowering the patient is, and always will be, a fundamental pillar of personalised medicine. Front-line healthcare professionals cannot treat a patient properly without taking into account his or her perceptions of value. They cannot treat a patient properly without taking into account that patient's lifestyle and, of course, they cannot treat a patient properly without creating equal access across the EU to the best possible treatments available. The authors of this article examine ways to enhance the empowerment of Europe's patients.

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A Bigger Role for Patients

Modern technology and the information highway have created new ways to put the patient at the centre of medicine.

Giant leaps in genetics have advanced certain key areas in healthcare, and have also led, at least in theory, to more patient empowerment [1].

DNA tests, for example, can throw up in advance the various likelihoods of major illnesses happening in an individual, although of course not everybody wants to know that they may have a higher chance of getting breast or colon cancer than their neighbour.

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Genetics has, as mentioned, opened new doors for patients in the form of personalised medicine. It has often changed the “patient journey,” with new treatments available and better communication between doctors and patients.

These days, there is more co-decision as lifestyle, work and personal preferences come into play – or should do, especially with front-line healthcare professionals who are up to speed with the latest developments, or know where suitable clinical trials are taking place and actually pass this on to their patients [2].

Patients are pushing to play a bigger role. And despite some who don’t believe that they should be doing so, it is a fact. Stakeholders in personalised medicine are carrying the message “Involve me!” and it’s not the best policy to “shoot the messenger” as King Boabdil did on receiving the news of the fall of his city, Alhama de Granada.

Healthcare professionals are still vital – the city is not lost – and the whole system that has taken centuries to put together since the time of Hippocrates should never be abandoned.

Of course not. That’s throwing the baby out with the bathwater, but patients need to play a bigger role [3].

Nietzsche wrote that “God is dead,” but healthcare professionals live on. Perhaps not as the “gods” that we all thought they were as children, but certainly as a vital driving force in the machines that are healthcare systems.

But we must remember that patients are at least one cog in the wheel that drives these machines [4].

Thinking Must Match the Science

With the internet and modern technology, and citizens who deserve the best treatment having contributed to healthcare budgets throughout their working lives, the patient has, and deserves to have, a right to the best care possible.

Arguably, many “old-school” physicians (and the medical schools that produce modern healthcare professionals) haven’t all grasped this [5].

Patients want to take control as much as possible of their treatment. Not as professionals, obviously, but as humans with a role to play. Some doctors need to put paranoia aside (that they are going to lose their “city”) and accept that a patient’s will for empowerment is not a “power grab” but simply a will and need to be involved on a meaningful level.

There is clearly a reformation going on in healthcare systems. But this sea change shouldn’t require the “Ninety-Five Theses” of the historical Reformation and needs to happen a lot faster.

We need new and clear thinking about the way that healthcare is delivered and there are excellent opportunities for positive change [6].

For example, the social fabric of how healthcare can be delivered must be allowed to grow and the role of ALL stakeholders should be recognised. This must be facilitated within bottom-up and top-down governing frameworks which will allow innovation to be integrated in an incremental and healthcare-friendly fashion that includes patient empowerment [7].

All the healthcare-friendly apps being developed in Silicon Valley and beyond will amount to a hill of beans if patients are not truly empowered.

And yet, and yet, things are moving forward in many ways, but the quality of an EU patient’s treatment still varies from country to country, depending upon resources and the incidence of a particular disease, and the awareness (or not) of potential over-treatment [8].

It is certainly a problem, but one that we must solve. As German Chancellor Angela Merkel said only recently: “We Europeans truly have to take our fate into our own hands.” She wasn’t speaking specifically about healthcare, of course, but the point still stands.

Patients are, for sure, not experts on medical matters. But they are absolute experts on their own lifestyles. As mentioned, some doctors still don't seem to fully understand that, and it needs to change.

Differences in Access

Patient empowerment is a central point of personalised medicine, but empowerment differs depending on the disease. Is someone with a rare cancer, with no clinical trial group within a thousand miles, able to be as empowered as someone with a breast tumour caught early and treatable?

What if the EU Member State is not the best at treating the condition, but suitable reimbursement is not available due to different costs in different countries with better resources in the particular case? (We have, of course, cross-border treatment rights, but anyone working in this area would have to say, honestly, that it is far from living up to its potential, however well intended.)

Another issue is that drugs for rare diseases are, obviously, more expensive given the smaller market and the cost of development, trials and safety checks and the time taken to get approval to go on the market.

The EU population is living longer, and is suffering much more from co-morbidities (many diseases at the same time). Resources are stretched. Yet patients are also better informed than they have even been (although too many "facts" on the internet can send self-diagnosis in entirely the wrong direction).

So, unsurprisingly, there is a debate about how much "power" a non-expert patient should actually have, and there is clearly a communication gap between the healthcare professional and the patient in many cases. Patients don't always ask the right questions, and many doctors are unforthcoming unless asked specifically.

Empowerment Is Key

As we know, personalised medicine aims to put the patient right at the centre of his or her own healthcare, and that means taking decisions in concert with doctors, nurses and surgeons.

This fast-moving area of medicine also advocates better training for healthcare professionals and smarter use of resources, as well as cross-border sharing of health data, better coordination and collaboration in research, and the continuous exchange of knowledge and best practices [9].

Personalised medicine applies to the actual diagnosis, the treatment and ongoing, often lifestyle-based post-care, which has the aim of (usually) prolonging life and (almost certainly) maximising the quality of life.

We are not in a position (yet) to change a person's genetic make-up to remove the possibility of a specific disease (although certain immunotherapy methods are coming to the fore which better target treatment), and there are huge disagreements about the value of population-based screening (largely because of cost and the aforementioned risks of over-treatment, as well as the dangers of radiation in some instances) [10].

But healthcare is surely all about giving the right treatment to the right patient at the right time, as well as about that all-important empowering of the patient. And, given that there are a potential 500 million of them spread across the EU's current 28 Member States, that has to be a worthy goal in itself.

Science is moving quickly. Let's move with it.

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