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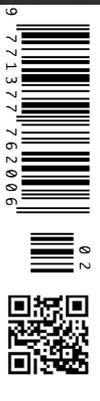
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# Is Patient Really Empowered in Medical Industrial Complex?

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A veteran patient advocate questions some of the hyped patient-engagement concepts and the reality of their practical applications within the ‘medical industrial complex’, and offers some strategies to change ‘the way we work’.

## Key Points

- In the medical industrial complex, stakeholders are distracted from the essence, i.e. the patient.
- There are many obstacles on the way to change, from the lack of money to disruptions in data flows.
- The notions of responsibility and ‘problem ownership’ should be brought into healthcare.
- Bringing together different stakeholders, creating the supportive environment, finding the root causes and working independently are key success factors on the way to patient-centred healthcare.

It may give us a pleasant feeling to think that the patient is well-informed, engaged and empowered. But I don’t think they are. With this in mind and due to another hype – ‘patient centricity’ – it makes me think of the Hollywood movies. When the director needed an Indian to get a shot of his pony, he shouted, ‘Go get an Indian!’ It’s the same with healthcare (or science that tries to help healthcare). When we explore new initiatives or set up projects in healthcare, we suddenly need a patient (‘Go get a patient!’) to fulfil the requirement that we really met one and had a discussion with them. In the end, the door closes and the decision is made in the same room by the ones who have always made the decisions over the past decades.

Most people feel uncomfortable to change their way of working and to change the balance of interests in the medical industrial complex (Kapitein 2018). Let me explain.

### Medical Industrial Complex

1962. In his farewell [address](#) to the nation, President and General Eisenhower made us aware of the military industrial complex.

*Armed forces, government and industry, working together in a way that doesn’t necessarily benefit the safety of the American people. Beware of the medical industrial complex.*

This was his message (my interpretation, you can watch his address on YouTube). This is a message and a warning from one of the most respected generals and presidents of the United States of America. He should know.

Ever since, more industrial complexes have grown. One of them is the ‘medical industrial complex’. Patient organisations, doctors, scientists, industry, government and health insurance companies/payers work together in a way that does not necessarily benefit the patient. I think there is no bad intention in this. It’s ‘the way we work’.

All industrial complexes suffer from distraction from their essence. This can relate to anyone or anything: the citizen’s safety, the army, the owner of a savings account, bankers. In the medical industrial complex there is distraction from the patient. Again, this is unintentional, but it happens. The further you are away from patient, the easier it is to make decisions that benefit your own interest and harm the patient’s benefit, which is quality of life. In this, there is a great difference, for example, between the empathy of a nurse and of an industry shareholder.

### Obstacles to Changing ‘the Way We Work’

The obstacles usually in discussion to overcome ‘the way we work’ are money, legislation, providing patients with better data and the lack of cooperation in healthcare. I think these are true and realistic.

- We lack money: but let us not forget that we spend an enormous amount of money on healthcare. There is enough money in healthcare, but the way in which it is spent is the problem.
- Legislation can be a problem: but the way we talk about the GDPR is wrong. The GDPR is designed and implemented to improve the flow of data across borders and between

institutions. And it is possible. Data however, are prevented from doing so by the institutions and the industry that do not want to share; they want to protect their own interests, and use the GDPR as an excuse.

- There are enough data or at least, there are many, but we do not even use the available data. Let's start with sharing and use of the existing data and see what we are really missing. This can be done in parallel.
- Be aware that when you ask patients whether or not you can use their data, they almost always say, 'Yes, you can,' but you do have to ask the question.
- Cooperation between science and healthcare seems to be a problem. Even during the COVID-19 times, we see dozens of initiatives to design, develop and test a vaccine. However, we continue telling each other that competition speeds up the process, even though we know that cooperation does.

These obstacles are valid but not the most important ones. Here are the two major obstacles.

discussions in healthcare and the decision-making process. There is, however, a second hurdle to take.

### Make It Your Problem

Problems in healthcare are not considered to be the patient's. It is the problem of the hospital that is not able to deliver care for COVID-19 patients. It is the problem of the oncologist that they can't help their patient with the right treatment. It's the problem of industry when medicines are not registered and do not get market access. I think that problems in healthcare are the problems of the patient and as long as we, patient advocates, do not act upon this, things won't change or only change very slowly.

Let me give an example. I have a lymphoma and that is my problem. I do need my physician to get over it and get cured, but it is and stays my problem. The same counts for many situations in healthcare. As long as we, patient advocates, tell industry, oncologists, pulmonologists and so

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### Responsibility

Because work in healthcare (and in most industries) is done in a flow, a chain of command, we become a part of these chains and are able to deny our responsibility. We can always say, 'It's not my responsibility, it's theirs, and I am not responsible for the outcome,' or 'The department or group is responsible.'

It was the German philosopher Hannah Arendt who worked extensively on this. In 'Responsibility and Judgment' (Arendt 2005) she explains the difference between legal and moral responsibility. Only this quality distinguishes us from animals: we as human beings have the capacity to think. Not thinking might feel comfortable, but if so, you step away from this important quality of ours. When thinking, we cannot look away from the results of our work, either individual or collective. This is because when we think, we are in a constant dialogue with ourselves. From Socrates we know that we have more problems with doing evil than with undergoing it. This brings in the element of moral thinking and responsibility.

As such, one big obstacle to deal with in healthcare is responsibility. Let's bring it back into our work and behaviour. Looking at the nurse and the shareholder, one might already have an idea on how to overcome this and how to improve the importance of the patient in healthcare; how to deal with changing 'Go get a patient!' into equality in the

on to solve the problem of the patient, it won't be solved quickly. So, when we, patient advocates, take the initiative and create cooperation between the different stakeholders of the medical industrial complex and bring them together, we take the first step towards solutions.

This is only the first, even if an important step. Many more have to be taken. Let's have a look at these.

### How Can These Obstacles Be Overcome?

One answer is value-based healthcare with patient centricity. It is an important step, but it's not enough and it mostly deals with economic aspects in healthcare: 'What's the price of one life year?' – the QALY concept. What we see with COVID-19 is that in an urgent situation this whole concept is thrown overboard. Taking the economic crisis into account, we spend over €20 million per QALY.

Let's look at how I think we can make progress.

### Put Different People in One Room

Back to responsibility. The nurse and shareholder example brings in the idea of 'putting different people in one room'. When we spend time discussing health issues in our own silo (whatever it might be) and have no connection with others, we will mostly consider our own interests. We automatically drift away from the essence

of healthcare: the patient. This doesn't mean that, for example, industry should only talk to patients or patient advocates. (Remember that a patient has a dependency on their physician. A patient advocate is independent and still has a strong bond with the ones they are representing, often a former patient or a loved one of a sick or diseased patient.) It means that industry has to work together with patient advocates, clinicians, regulators, health insurance companies, or payers.

When doing the right thing and doing it well, all stakeholders should work together in the same way as the patient advocate.

How do you get them into the same room?

Evidence is important but not enough. There is so much evidence and science on the shelf. We do not act upon what we already know, and this is preventing us from doing the right thing. In order to bring these ideas to reality, we need to get certain things in place, alongside evidence.

### **Build the coalition of the willing**

Different people should be willing to assist you in your mission, with your project. The ones who are 'willing' are usually easy to find. It is the inner circle you already know, but you also need people with a critical and positive mind. Don't look for the automatic, 'Yes, I agree' type of person. Find the people who criticise you and bring them together to work out the action plan.

### **Build the coalition of the ones who pull the strings**

This is difficult and they are not always easy to find. Some are obvious, like MEPs, ministers, CEOs, project managers, but sometimes it can be the person with a long track record in an institution; it can be the partner of the one who you think is in charge. It takes time to find them and it takes time to involve them in a facilitating and cooperative working position. When you have achieved this, the real work can start. You can gain help in finding these facilitators by asking the people you know in the coalition of the willing. They already know most of them and have an established personal or professional connection with them.

### **Go for Root Cause**

It is important to realise that all stakeholders have their own interests. When industry tells you that their first interest is the patient, this is simply not true. It can't be. Theirs is the shareholders', and this is not unjust. It's a logical consequence of the existence of industry in healthcare. The same counts for scientists: their interest is to deliver science, publish, and find new funding. There is only one stakeholder who holds the patient as their first interest: the patient advocate. The patient advocate places the patient in the centre of healthcare and shows us the reason and essence of what healthcare should

be. Therefore, they ought to be in that room.

When all the stakeholders make clear what their real interest is, it's important for them to know what the other really thinks, even if it makes them uncomfortable. This struggle for betterment and truth moves us forward.

### **Be Independent**

Nobody is independent, but we should strive for it when we want to do the right thing and when we want to do good. You're doing good when you make other people flourish and when you contribute to society, to healthcare and to the quality of life of patients.

It helps to be with different people in that room. It helps even more when you come to a consensus to go for the root cause.

### **Scale Fast**

It's important to start working together on an equal basis and to move forward in a trial-and-error way. Yes, when innovative, you're allowed to make mistakes and by criticising each other in a constructive way, you're able to 'think big, start small and scale fast'.

### **Empowered Patient and Healthcare Systems**

An empowered patient is a well-informed patient. The problem is (be aware that I'm dealing with cancer) that the moment you become a patient you're, by definition, metaphorically illiterate. You become literate during your journey, through life as a patient, but at the start you know almost nothing. Even the doctor who is diagnosed with cancer is helpless in the first moments of their illness. Therefore, the stakeholders in the medical industrial complex have to build a healthcare that promotes excellent care. And we can. I described how to overcome the obstacles, and providing healthcare this way we can arrive at a situation where patients are taken care of in the right way (where quality of life is ranked highly as a state or as a means) and evaluate their care as 'perfect'.

Am I dreaming? Of course, but realism is the biggest enemy of hope, and hope is the energy we all need in life to keep us dreaming and alive. As is love for one another.

### **Conflict of Interest**

None. ■

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