



People change through adaptation and because of urgency

Peter Kapitein

Inspire2Live, Amsterdam, The Netherlands

Correspondence to: Dr. h.c. Peter Kapitein, Inspire2Live, Noorderakerweg 271-B, 1069 LT Amsterdam, The Netherlands. Email: peter.kapitein@gmail.com.

Received: 10 June 2019; Accepted: 20 June 2019; published: 02 July 2019.

doi: 10.21037/pcm.2019.06.02

View this article at: <http://dx.doi.org/10.21037/pcm.2019.06.02>

I am one of the founders of an organization that raised an enormous amount of money for cancer research, with the all-time high of 32 million euros in one year (2012). We donated this money to the Dutch Cancer Society and it was spent on cancer research. From as early as 2010, we had this feeling that we need a lot of money for cancer research but the most important questions did not come to the table: “Are we doing the right things?” and “How do we spend money in a way that has most benefit for patients?”

Why, so often, do we gain knowledge through excellent research but do not implement this research? Why do we not execute what we already know? To quote Sir David Lane: “When you don’t execute what you already know, it’s a bloody scandal.” I most certainly agree and would like to add: “And we lose too many patients because of this.” Therefore, change is needed in healthcare because it appears that it doesn’t update itself in practice at the rate it produces knowledge on improvement.

“Changing healthcare is like moving a cemetery.” This is what I often say in my talks and I think it’s not only true for healthcare but it’s also true for all the changes that we think necessary to benefit people in general. People don’t want to change, it appears. They talk about it a lot and they adapt but only when there is an urgency. It’s important to realize that I think there is a difference between change and adaptation. If you change your behavior you do this with consciousness. You realize yourself that you need to change and are willing to change and therefore you change. Most times we do not want to change but external factors or incidences (like a diagnosis with cancer, or the loss of a loved one, or less dramatic the loss of work) force us to adapt to a new situation. We do not want to but we have to. I think this is what most of the times happens to us.

An important book of study is ‘Thinking fast and slow’ from Daniel Kahneman (1), the scientific partner and

friend of Amos Tversky (two well-known psychologists that contributed a lot to society). Kahneman got the Nobel Prize for economy for his work (Tversky not, because of his death of a melanoma before the Nobel Prize was given to him). The reason was that they discovered what human behavior implicated for the choices that consumers and producers make in the economy. The leading thought in economy was (and still is) that people are driven by the urge of winning. This appeared to be untrue and Kahneman and Tversky taught us through their work (and the work of many other excellent scientists), that there are other motivators even more important in the choices we make. Kahnemans statement in ‘Thinking fast and slow’: animals, including humans, fight harder to prevent loss than to win.

I happened to see my cat defend his property when a new cat in town arrived. Within seconds he made clear to his competitor that it is not allowed to enter ‘his ground’. With an aggressive and fast attack, he defeated the competitor and was ‘ruling’. The next day, when my cat walked into the property of his neighbor, the same thing happened and my cat returned home injured. The lines were drawn and hopefully, they can now live in harmony understanding the rules.

Now back to humans and human behavior. What Kahneman teaches us:

In human affairs, this simple rule (PK: the one I mentioned above) explains much of what happens with institutional reforms, corporate reorganizations and corporate restructuring, and attempts to rationalize bureaucracy, simplify the tax system, or reduce medical costs.

However, if the parties involved have some political influence, potential losers will be more active and tenacious than potential winners. The outcome will therefore turn out to be to their advantage and will inevitably be more expensive and less effective than originally planned.

Back to healthcare and changing healthcare. We all know that when you perform a certain task more often, your work improves, you become faster and the quality of the output rises. There is a lot of data available about standards in quality and the volume of surgeries and it appears that when you practice more, the quality of your output improves. Let's take as an example (among many), esophagus cancer: In England, agreements were made in 2001 to concentrate care around an esophagus-gastric center that provides for a population of at least 1–2 million inhabitants. In addition, this center had to have a minimum of four to six specialist surgeons, each of whom performs a minimum of twenty resections per year and provide continuous care for their patients. In the 2004–2008 period, the 30-day mortality rate dropped from 7.3 to 4.1 percent. In 2013, a further reduction was achieved to 1.7 percent for esophagus resections and 1.1 percent for stomach resections (2).

Several investigations have been done and they all showed: when you practice more, your achievements improve. Now what prevents us from moving towards excellent cancer centers where specialists have defined what the criteria for these centers are and where the best specialists work? Why is it so difficult to concentrate and to specialize? It saves lives. In other words: our irresponsible behavior kills a lot of innocent patients and we let this happen. This is our responsibility!

People don't want to change; they talk about it a lot and they adapt. I mentioned it before. Adaptation is an important human trait. It's the reason that we, homo sapiens, are still here. And we adapt when there is an urgency for us to do so. Otherwise we don't move. I believe that the main reason we don't change healthcare (or even better: we don't adapt healthcare to the latest findings in research) is that there is no urgency involved in healthcare, at least, not in the board rooms of the hospitals, at the ministries of health, within industry, within health insurance companies and also not in research.

I think that there is an urgency with nurses and some doctors; nurses especially, because they work and care for patients all day and often until they die. They witness how we treat them and, most of all, they have to answer all the difficult questions that patients ask. We place nurses and some of our doctors in impossible difficult situations, asking them to provide patients with answers that are impossible to give. How has it ever come to this? With our discussions about money: healthcare is too expensive; quality of life: it is not the patient who chooses their quality of life; and quality of care: it is not the patient who chooses their quality of

care, we have driven away from the essence of healthcare: the patient. Healthcare has changed over the years and in his book 'Deep medicine', E Topol concludes (3): "This is where we are today: patients exist in a world of insufficient data, insufficient time, insufficient context and insufficient presence. Or, as I say, a world of shallow medicine."

Healthcare is too expensive

"Healthcare is like dogfood business" (4). I wrote an article about this. Dogs don't choose their own food and don't pay for it; similarly, patients do not choose their own treatments and they also don't pay for them. We created a market where the main stakeholder, the patient, plays a passive role. This is not a market. It's a market when you buy Pepsi Cola because you prefer Pepsi over Coca Cola and you tell me: 'Hey, it's my choice and my money! We have created a market, a way of working, where 'the more patients the better' rules. We pay per performance and should not be surprised that the stakeholders in healthcare perform with their results and outcomes.

A painful example is diabetes. There is a lot of scientific evidence that diabetes type 2 can be cured by lifestyle interventions. Even so, most doctors prescribe medicines and don't discuss the benefits of an improved lifestyle with their patients. This is why there is a hundred billion drugs on the market for diabetes. From an ethical perspective, this is a criminal act. From an economic perspective, as we are spending tax payers' money in the wrong way, this is an economic crime.

Healthcare is expensive because we have made a market of it.

It is not the patient who determines the quality of life

Whether it's in parliament, at the ministries of health, in hospitals or in the boardrooms of industry, we talk so much about the quality of life for patients. We say that it's important in the decision making to be taken about developing medicines, about whether we treat or not treat, about access of medicines to the market and so on. But I am asking you: whose quality of life is at stake? Patients have a clear vision on what they value in quality of life. And all these changes over time. When our time comes, we know when enough is enough and when our life has been lived and should end. It is simply not true that patients always want more treatments. They have a clear idea about what is

important and their decisions are based on this. Yes, when your grandchild is due to be born in 3 months you simply undergo that treatment to see that moment but when your quality of life is nil because you're 100% incontinent, you're 78 years old and only offered another 6 more months with no improvement, what is the point?

It is the way in which we work and have organized healthcare, that is responsible for unnecessary treatments and the high costs that this ensues. Bureaucrats, politicians and lawyers talk about the topic 'quality of life' and we patients have no say in it! There is talk about shared decision making but it's not practiced.

Patients are the experts on their quality of life and don't ask for treatments with no added value. They are also the only ones who can take decisions regarding risk.

It is not the patient who determines the quality of care

When I speak of quality of care I mean the quality of the governance of the institute that delivers the care. When delivering care, you should know about the care. You need skills that relate (among other skills) to the people that are the subject of the care: the patients. In my opinion it is not good when one governs a healthcare institute but doesn't work with patients. It is not good when we do not have patient advocates¹ in the position of making decisions. Patient advocates know what they need. Of course, this does not apply to all of them and many of them will not want to be in that position, but when you want the highest possible level of quality of care, you need to make decisions involving patients: patient advocates need to be part of the board of the care institute. This is essential when we want to bridge the gap between the care institute and patients.

What is at stake for the holders?

Looking at the stakeholders, what have they got to lose when the balance in healthcare shifts towards patients?

- (I) For researchers, it means that patient advocates will make decisions, together with them, on what research will be done. When pancreatic cancer patients are asked what the most important thing is

for them to deal with, they respond, 'pain'. When we take away the pain, we can give them 6 to 12 months more with a better quality of life. Nobody is doing research on pain because we simply don't ask patients how they feel and so we don't know what research is required. Doing this would mean that the research would have greater output, would be of greater benefit to patients. The researchers, themselves, would have greater satisfaction and meaning to their work, depending on the reason for their work;

- (II) For doctors and hospitals, it means that the board will consist of a patient advocate, a nurse, a doctor and an accountant as it's good to have someone in charge of the finance. This means that the quality of the output will rise because the decisions are made by people who know what they are talking about because they are all experienced in healthcare;
- (III) For nurses, it will mean that they do not have to answer a lot of difficult questions anymore because healthcare is led by people who know about health and care and have a stake in it;
- (IV) For industry, it means they do research on treatments decided on in cooperation with patients. Trials will be designed in cooperation with patients so that patients become real advocates for treatments with a high added value instead of patient representatives being paid by industry to tell everybody about the added value already determined by industry and their shareholders. This is the hardest hurdle to take as added value for patients will, in certain situations, conflict with the shareholder's value. From my experience, I have been informed that it is the shareholders who have invested in the business. We need the patient's life and care to be at the heart of this;
- (V) For the government and regulators, it means that regulation is based on patient preference. Think of data that is now decided upon by bureaucrats, lawyers and politicians: the monopoly on making rules on their own will vanish. As a consequence, regulations would help patients instead of only

¹ I make a difference between a patient and a patient advocate. A patient has a dependency on the physician and healthcare. A patient advocate is an independent advocate for patients in healthcare. There is no dependency allowed on parties that have an interest in healthcare (pharmaceutical industry, suppliers of medical equipment, etc.).

protecting healthcare workers from getting sued by patients. This danger disappears because of the bigger influence that patients would have on healthcare;

- (VI) The reimbursement of care is a difficult one to address as this differs in every country. What is essential is that what is reimbursed and what should not be reimbursed should be determined in cooperation with patients. Don't be afraid to put patient advocates in this position. I believe that healthcare will become much less costly because we, as patients, don't want treatments without added value. Because we pay per transaction, we will have fewer transactions.

We need urgency in healthcare to bridge the gap with patients

When we return to Kahneman and realize that people fight harder to prevent loss than to win, we know for sure that we need patients and patient advocates as they have a lot to lose: their lives. Think of the AIDS activists in the nineties of the former century. They knew they were all going to die in a year or so. They fought so hard that they forced science, doctors, government and industry to change their attitude and ways of working so that, in the end, the combination therapy was discovered, registered, reimbursed and prescribed. They were the ones that worked the uphill battle and had the combination of knowing what they were talking about (they were all citizen scientists), lobbying and influencing at the highest level, and also knowledge of public relations, marketing and media in the right position.

The beauty in this is that to bridge the gap in healthcare, we need the patients, on the one hand, to be the most important ones in healthcare and on the other hand they are the ones who have nothing to say in healthcare at this moment. The person in the center who has no part in the decision-making process in healthcare, can help us to create a situation with better, faster and cheaper treatments and processes in healthcare than we have today.

Is that all there is?

Is urgency all we need to adapt? No, certainly not. We need to have a vision on what we're aiming for in healthcare and research. If it's simply doing research for the sake of research, we will not proceed in the speed we need. The vision will need the cooperation of patient advocates,

researchers and clinicians and depending on the direction and the topics we need to work with government, industry and health insurance companies as well. Based on the vision we must build our strategy to accomplish a lot of work and together with all the stakeholders. A vision and strategy are important and might be a topic for a new insight and article. But let us never forget the patient advocate to join at all moments, otherwise the interest of the most important stakeholder will not be at the table and the result will be inefficient and ineffective.

Urgency leads to adaptation. The urgency in healthcare is the patient. We can and should ask the patient to help us improve healthcare. The beauty is in the inevitability that this will happen.

Acknowledgments

I would like to thank Piarella Peralta (Patient Advocate Inspire2Live and Diaceutics), Wim Schellekens (Senior Advisor Healthcare), Sjoerd Repping (Professor Healthcare at Academisch Medisch Centrum of Amsterdam) and Herman Otten (Patient Advocate Inspire2Live) for their critical remarks and advice. They have been of great value for me. This does not mean that this article necessarily reflects their opinion. I would also like to thank Barbara and Mark Moss for their final touch on the English language and their contribution as a patient advocate.

Funding: None.

Footnote

Provenance and Peer Review: This article was commissioned by the editorial office, *Precision Cancer Medicine*. The article did not undergo external peer review.

Conflicts of Interest: The author has completed the ICMJE uniform disclosure form (available at <http://dx.doi.org/10.21037/pcm.2019.06.02>). The author is the CEO and Patient Advocate of Inspire2Live. The author has no other conflicts of interest to declare.

Ethical Statement: The author is accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Open Access Statement: This is an Open Access article distributed in accordance with the Creative Commons

Attribution-NonCommercial-NoDerivs 4.0 International License (CC BY-NC-ND 4.0), which permits the non-commercial replication and distribution of the article with the strict proviso that no changes or edits are made and the original work is properly cited (including links to both the formal publication through the relevant DOI and the license). See: <https://creativecommons.org/licenses/by-nc-nd/4.0/>.

References

1. Kahneman D. Thinking fast and slow. Penguin books, 2012.
2. van Hillegersberg R, Wijnhoven B, van de Velde C. Complexe Slokdarm- maagkankerzorg verder concentreren. Medisch Contact. 24 September 2014. Available online: <https://www.medischcontact.nl/nieuws/laatste-nieuws/artikel/complexe-slokdarm-maagkankerzorg-verder-centraliseren.htm>
3. Topol E. Deep Medicine: How Artificial Intelligence Can Make Healthcare Human Again. Basic books, 2019.
4. Kapitein P. The payer determines but it's not the patient. HealthManagement. 2018. Available online: <https://healthmanagement.org/c/healthmanagement/issuearticle/the-payer-determines-but-it-is-not-the-patient>

doi: 10.21037/pcm.2019.06.02

Cite this article as: Kapitein P. People change through adaptation and because of urgency. *Precis Cancer Med* 2019;2:22.