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More than just information.
The transparent patient from an individual perspective.

Introduction

This contribution focuses on the experience of being transparent as an individual regarding one's own health data and on what this means to the individual. Technological advancements lead to new measures that quantify the health-related aspects of individuals, such as digital technologies used both for tracking individuals behaviour as well as informing them about the state of their health, and genetic testing. They also allow, to some extent, to shed a light into the individual's past, present and future health and disease progression. However, what does this new transparency mean to the individual?

Collecting information about an individual usually does not require a big effort. Giving a blood or saliva sample for a genetic examination or use of health apps is done easily and quickly. However, the collection of such information can deeply influence an individual's life in a psychological, social and economic sense.

In this essay, we will discuss the possible benefits and risks for individuals that come along with this increased transparency due to new technologies. We will also discuss its impact on the social environment of the patient, the need for professional counselling and understandable information in an area where we can diagnose ourselves with self-collected data, by using internet-based tools, doing genetic tests through online companies, or collecting data about our mental status through apps.

We would like to put an emphasis on the term "patient" that will be used throughout the essay. The patient is not only a person who stays in a hospital. To fully understand the whole spectrum

of states that mean "being a patient", we should consider it as a continuum: from first risk factors and the beginning of an illness, through being diagnosed, cured, to the full recovery. Here, we want to put an emphasis not only on 'current' patients but also on patients who suffered from certain diseases in the past and those who may experience health difficulties in the future. We believe that comprehension of the proposed continuum is a crucial factor of understanding mechanisms behind diseases - many people who already suffer from illnesses are not yet diagnosed, thus not cured properly. At the same time patients who already recovered from certain diseases, after complete treatment are left on their own, without any additional support - what results in returning to the same or other illness based on similar mechanisms.

Transparency increases knowledge about oneself

Transparency understood as a self-monitoring simply may be "fun" for curious people who are interested in how their body works and how their experiences modulate their behaviours and mood fluctuations. With the use of this kind of data, they can sculpt their environment and make it as friendly and supportive as possible. This increased self-awareness - or self-knowledge may lead to high improvement in the overall well-being and health situation. Sometimes a slight change of behaviour, environment or diet may eliminate the symptoms of the disease completely (for instance, with gluten or lactose intolerance, dust allergy, work stress etc).
The digital healthcare tools may be a wonderful solution for many other issues like, for instance, keeping patients involved in treatment and boosting its outcomes, improving communication between patient and doctor or psychotherapist and last but not least, it can possibly lead to a better understanding of disease - for both patients and doctors. What is more, even with maximised efforts from doctors' side, patients find it very important to feel that they are able to track cure process by themselves (Hsieh, Dey, Forlizzi, Hudson, 2008).

Unfortunately, we do not live in an ideal world and such a high level of self-knowledge may also lead to developing potential risks, for instance, over-self-diagnosis with use of internet-based tools, avoiding contact with medical doctors, putting less trust in doctors' decisions or - on the contrary - hypochondria, checking every symptom with the specialist, forcing family and friends to visit physicians more often. All these circumstances are elaborated in the next paragraphs.

Empowering the individual

One can argue that there is a general and logical connection between transparency, knowledge, autonomy and competence. If information regarding my health status or health behaviour is transparent, I gain a deeper understanding of my illness. I need this knowledge to decide and act autonomously and self-responsibly. Only if I have this knowledge and the corresponding autonomy, I can develop health competence. Only if I feel autonomous and competent, am I motivated to follow recommendations from my doctors regardless of constraints. Therefore, transparency in healthcare can have an important impact on enhancing the patients' treatment outcome.

For example, in the ideal case, if patients could easily access their medical data and track their health behaviour, they would gain a better understanding of their disease and factors that influence it and may become intensively involved in the treatment process once they realize how their behaviour can promote recovery. The talk presented by our colleague, Jasper Bouwsma on Health Data Through Citizen's Eye, showed that once patients gain expertise on their disease symptoms, and on how their behaviour interacts with recovery, it empowers them to be an expert on their disease and to be able to discuss with the physician on the same level of knowledge. All of a sudden, a patient doesn't have to blindly follow the recommendations of the physician but can use data supporting his or her arguments. Of course, nobody expects that machines or patients will take over the whole diagnostic process (with all the nuances and sensitivity of the procedure) from educated and experienced specialists but often the new solutions may offer valuable support and simply speed-up the process.

Furthermore, by learning about possible future disease risks, even healthy individuals get a chance to become proactive and make individual choices regarding their lives. This can increase their health competence and give them control over their own health. For instance, knowledge about an increased genetic risk to develop breast cancer gives individuals the opportunity to take preventive measures. First, they can opt for regular breast cancer screening, which is also covered by health insurance if a genetic risk is diagnosed. Second, they can opt for a prophylactic mastectomy, which would reduce their risk of breast cancer to the level of the general population. However, there are also genetic diseases, such as Huntington's disease or Alzheimer's disease, which today cannot be prevented even if the predisposition is diagnosed very early. Still, individuals might perceive knowing about such a genetic predisposition as

increasing their autonomy, by adapting their life decisions to their future "fate". For example, an individual might change their life priorities and avoid postponing things that are important for them. They may start working part-time, go on a world tour or have children at a young age.

Early alarm system

Next to strengthening the health competence of patients and individuals in general, transparency and further knowledge on how the behaviour is linked to the disease progression and recovery, could be integrated into an early alarm system.

For example, the method of passive mobile sensing allows for monitoring the progression of mental disorders. If this connection between mobile phone usage patterns and their connection to mental states has been reflected back to the individual by real-time feedback, patients and practitioners could intervene just-in-time before a psychosis or a maniac episode breaks out.

Another area of use of such early alarm systems is the field of suicide prevention. Such emergency apps for suicidal patients could warn the patient and the caregiver if the interaction with the phone changes in a way that indicates a possible suicidal crisis. This is especially important as it is important to reach suicidal patients before they fall into the so-called suicidal tunnel. Yet another example where an early alarm system would be helpful is relapsing after discharge. Barnett and colleagues (2018), in their study, were able to identify changes in mobile phone usage patterns of patients two weeks prior to relapse. If we could develop an early alarm system app on the basis of these patterns, it would be possible to prevent serious relapses, which are very demotivating and stressful for the individual and very cost-intensive for the society.

These mobile phone interventions could be event-based and triggered through these mobile phone usage patterns, as mentioned in the presentation of Marta Marciniak. Such an early alarm system would take away much of the pressure and fear of patients who try to figure out everyday life again after inpatient treatment in a psychiatric clinic.

Genetic tests, as another example, might provide individuals with valuable information about future disease risks. For example, knowing about an inherited cancer predisposition allows for screening at a young age to detect cancer early. In other cases, such as *Familial Hypercholesterolemia*, drugs can be taken that reduces the risk of sudden heart attacks.

Information overload

Transparent patients collect a lot of data and gain knowledge about themselves. However, not all individuals are prepared to deal with that amount and sensitivity of the information. Some may feel overwhelmed by the amount of information that is collected about them or by the many new decisions that are expected from them based on this new knowledge.

For example, genetic testing is one application that requires attention in this field, especially if we consider its complexity and potential impact. Predictive genetic testing gives healthy people information about medical risks they may develop in the future. These risks are usually marked as probabilities and do not provide certainty of whether a disease will develop or not, even if genetic testing gave a clear result. Most importantly, every individual has the right not to know, therefore it is their own decision whether to undergo predictive genetic testing or not (Evans et al. 2001). Also, after getting the results, the individual has to make a decision if he or she wants to tell their family about the possible risks and the family has a right to decide if they wish to be informed or not.

What is very important from a psychological point of view, is that the patients have not been trained to use this kind of tools in their treatment plans. Thus, the introduction of the new technology and the amount of information that is coming with it might also cause the unpleasant feeling of being overwhelmed. The question is whether the healthcare system will provide additional support to the patients to teach them how to use the new technologies and on how to interpret the data in a meaningful way. As we could see in the video "Uninvited Guests" presented by Martina von Arx and Giovanni Spitale, individuals sometimes just want to live and not to spend additional time for understanding the data or follow the recommendations for a longer or healthier life. Especially if these recommendations are not in line with their personal goals but instead, are just general recommendations of health experts. This has been also summarized by the input of Jasper Bouwsma, who is also a patient himself: "If you are already sick and have to struggle so much with your disease and the symptoms, you just want to live your everyday life as normal as possible and not follow any recommendations by some random health app."

Psychological distress

As mentioned in the introduction it is easy to say "it is just information, what bad can come out of it". However, information always comes with new knowledge, new decisions and new responsibilities and all of that can cause psychological distress. Especially unsupervised access to one's own health data and diagnosis may lead patients to a significant decrease in their mood and mental stability. The personal story of Daniel Wamunga who shared with us information of his brother demonstrated that it is very important of what kind of narrative a doctor uses to tell us about our symptoms. Biopsychosocial explanatory models of diseases have shown us that stress plays a major role in disease development. More stress leads to deterioration, less stress leads to an improvement in my symptoms. If I am now left alone with my diagnosis, as can be the case with health tracking instruments, I may experience a lot of psychological distress and my health status will worsen.

This is especially true with genetic testing as it looks at the risks to develop future diseases. Once such a risk is determined, it is difficult for some affected individuals to go on with their lives as usual. They may live their lives waiting for the disease to develop. For example, knowing about a genetic predisposition to develop a neurodegenerative disorder might cause panic whenever an affected individual feels tired, confused or forgets something he or she wanted to remember. This can diminish their quality of life. Individuals might wish to never have learned about their risks, but have no way of "un-knowing". Furthermore, as such genetic test results are never 100 percent certain, individuals still live with some uncertainty. This is an interesting illusion of transparency. Individuals often imagine that transparency and knowledge about themselves give them control, but in the end, nothing can be taken for granted and control through transparency is a figment of the imagination.

Another issue of transparency that negatively impacts the patients is the problem of "trying to fit a diagnosis". This observation is known in the field of actual physical health. Here some patients report more symptoms when they already know what they suffer from. This bias could be reported more often when individuals with the use of their health data trying to find the right "diagnosis" by themselves.

A similar problem becomes true for many disorders with the concept of self-fulfilling prophecies. For example, if one continues to monitor their mood throughout the day and they realize that they continuously mention a bad mood, they may start to think and become more and more convinced that something is wrong with them and develop a depression as they become focused on the negative mood results and stop taking the context into the consideration.

To summarize this paragraph, transparency through health tracking and knowing about your risk for the future disease could actually lead to the development of disorders either through the psychological distress or by the mechanisms of self-fulfilling prophecies. Without the medical knowledge and expertise to put the symptoms in perspective, the new technologies could cause a higher number of over-self-diagnosis and hypochondriac patients.

Professional counselling

Collecting health-related data increases individuals' self-awareness of past and present illnesses or future disease risks. While this has the benefit of empowering people to adapt to these dangers and possibly even prevent them, we have also illustrated considerable risks, which mostly make an impact on psychological well-being. Many of these risks can be minimized by accompanying the collection, analysis and interpretation of health-related data with professional counselling.

Trained medical doctor or psychologist may be able to teach the patient how to deal with the data, how to analyse and interpret them but at the same time - how to distance himself from this knowledge and to avoid drawing too many and definitive conclusions. Without this kind of assistance, the risk of developing depression, anxiety, hypochondria and many other mental issues is much higher. Stakeholders have to be aware that revealing this kind of information may expose people to additional stress and even put their life and health in danger. The phantoms of avoiding physicians, self-diagnosis with the help of internet tools, self-fulfilling prophecy, fitting to the diagnosis are strongly connected to the topic of self-knowledge.

One of the solid examples may be the growing popularity of genetic testing, particularly those of predictive nature. Individuals get more and more insights into their genetic risk factors. Thus, transparency inevitably increases both for the individuals themselves as well as for the whole society. Genetic counsellors can and should play an important role in these scenarios by providing adequate and reliable information that gives the laypeople insights into these highly

complex problems. Especially because the genetic information always involves potential knowledge for relatives, since they could have inherited the same genetic variance. Sharing such information can be especially challenging in disrupted families or when family members do not want to know about their future health risks.

Conclusions

We tried to illustrate that health-related transparency comes with benefits and risks for individuals and their social environment, using both our knowledge and inspirations from various topics that were discussed during the Autumn Academy in Engelberg.

If health-related information becomes more transparent, individuals have the chance to gain a deeper understanding of their health status, which might help them to decide and act autonomously and self-responsibly. We believe that the potentials and benefits behind transparency are great for the individual, especially in regards to strengthening the autonomy, voice and health competence of each patient. Furthermore, the developments in early alarm system and the opportunity to higher up the prophylactics, will reveal bigger support of vulnerable populations. Additionally, the access to diagnosis, health interventions and treatment support is easier for populations that otherwise would not have access to treatment, for instance, people in certain low-income areas that often do not have access to healthcare, but they almost all do have a phone (Naslund et al, 2017).

However, as we have discussed too, transparency entails risks and it depends on the individuals' life philosophy what extent of transparency is safe and comfortable for them. Some individuals might easily feel overwhelmed with the vast amount of information and autonomy and thus might feel stressed and start to develop psychological problems. Many people in the psychiatric setting report difficulties in overcoming the subjective, unpleasant gut feeling of becoming transparent. Whenever sensitive information becomes transparent there is a risk of involuntary exposure, of misuse, of stigma and misconception. Therefore it is very important for us as a society to think about how we want to integrate these new technologies into our health systems. As Group 3 was discussing from different perspectives, we need a public debate that integrates all affected stakeholders.

With the increasing use of technologies that collect health-related data, it is important to raise awareness among the general population, to increase their knowledge in order to make informed decisions. People must be informed about the benefits and necessary tools to cope with the risks of transparency. The Autumn Academy has been very inspiring in shedding some lights on the unresolved issues in regards to the transparency and how it impacts the patient. We take out that it is very important to define the narratives in which we want to see our future. As Sophie Wagner interestingly argued these narratives become imaginative horizons that will shape our future. Therefore we want to conclude with some open questions we have to focus on the future as they become more and more important. Andrea Martani who focused in his presentation on the individual's own responsibility and duty in regard to the finite resources of the healthcare system indicated: What should happen with patients who do not want to become transparent? How do we protect them or should we not protect them? How do we prevent a blame game if these new technologies to track diseases and health deviant behaviour lead to mass surveillance? Who will we pay for these apps and tests? Who will be accountable for the quality of the technology, its results and their interpretation?