

The Tyranny of Numbers

How e-Health Record Transparency Affects Patients' Health Perceptions and Conversations with Physicians

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Abstract

All Danish adults have access to their electronic medical records on the e-health platform Sundhed.dk, which is intended as a means to empower patients. But what happens when patients see their paraclinical test results presented as numbers which are flagged as either 'normal' or 'abnormal'? Based on fieldwork in general practices and consultations, and on observations of individuals living with chronic illnesses, we investigated how patients and physicians interpret and interact with such numerical values, creating, as we argue through the words of Gregory Bateson, 'epistemological errors'. We show how health record transparency blurs the patient's senses and understanding and makes it harder for them to interpret their state of health and to trust the clinical judgement of health professionals. We argue that the immediate access to test results triggers a runaway process in which numerical values (be they normal or abnormal in comparison with a standard point of reference) transform into a threat to life itself. As such, our ethnography underlines the intricate contradiction between the trust placed in biomedical sciences and the uncertainty involved in testing, diagnosing, and treating. Patients' access to all test results leads to a quest for certainty—one never fully obtainable, which thus instead mobilises new uncertainties.

Keywords

Numbers, Patient autonomy, Transparency, Runaway process, Uncertainty.

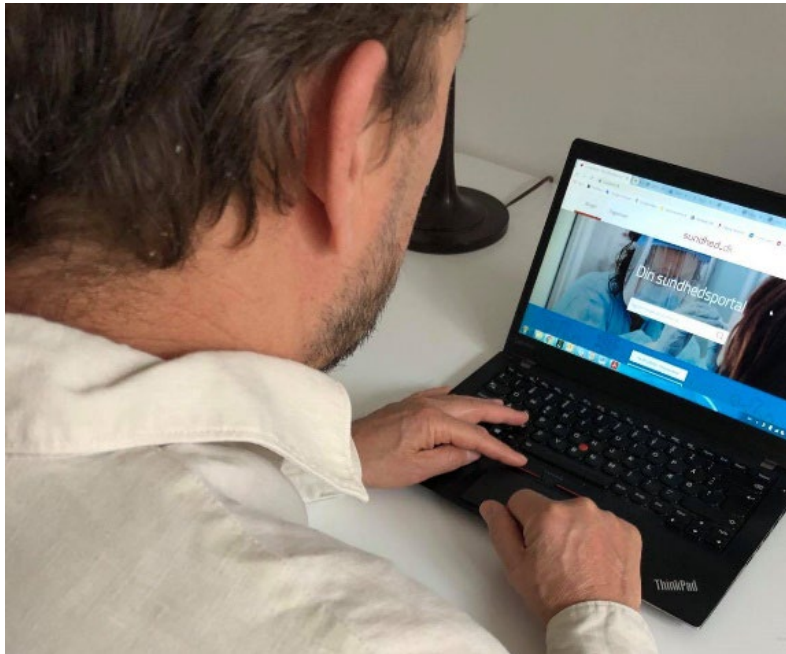


Figure 1. John accessing Sundhed.dk from his living room. Image by Alexandra Brandt Ryborg Jønsson, 2021.

Introduction

You told me that the blood sample was fine. But I checked it on Sundhed.dk, and I could see that I have elevated liver enzymes, and then, of course, I got nervous ... Then, I googled it and I saw that I have cancer ... I just want to check this up with you, because when I saw the number I started to worry that I might be seriously ill (Hanne, a 66-year-old patient, talking to her GP during a self-initiated consultation).

Clinical practice guidelines often identify specific numerical diagnostic criteria and treatment goals in relation to a disease. The specific purpose of these numbers is to enable one to determine whether numerical values are normal or abnormal when compared to a reference interval. In Denmark, as elsewhere, direct access to paraclinical test results was for a long time reserved for medical professionals, whose expertise was considered so complex and esoteric that ‘only properly trained men can know and evaluate it’ (Freidson 1988, 360). Over the last two decades, however, the digitalisation of medical knowledge has, as predicted by Eliot Freidson (1988), challenged the ‘knowledge gap’ between patient and doctor, enabling patients to engage critically with their health (Topol 2015). To take a contemporary example, the COVID-19 pandemic has made manifest the democratisation of knowledge, with ongoing discussions taking place on social media—including celebrities endorsing or sharing COVID-19 theories and thus presenting a challenge to established health authorities (Berlivet and Löwy 2020).

Policymakers and other prominent opinion formers commonly portray health record transparency (that is, patients' direct access to their own health records) as an effective means of challenging the paternalistic power of doctors, by empowering patients to engage with doctors as a partner, thereby ensuring a more democratic relationship (Olesch 2016; Topol 2015). Medical information about the individual that is contained in their health records has heretofore been a 'secret', conferring power on the medical professional and allowing that power to be exercised over others. Digital health record transparency promises to put an end to this secrecy. Thus, a commitment to transparency [*gennemsigtighed* in Danish] is being used to advocate for a shift in healthcare services in which patients' access to their own records can challenge what Foucault identified as the nexus of knowledge and power (Foucault 1980).

Today, all Danish citizens aged 15 years and above can log on to Sundhed.dk using their digital signature and social security number. There they have access to their personal health data, including paraclinical test results, X-ray reports, notes from hospital visits, vaccination records, and details of their individual prescriptions. People in Denmark, as in many places around the world, have been asked to test regularly for SARS-CoV-2, the virus that causes COVID-19, and mobility, work, education, and other elements of life are being regulated based on infection data. Danes can access individual results and aggregated COVID-19 numbers on Sundhed.dk and, as a result, the use of the digital platform has doubled since the beginning of the COVID-19 pandemic (Ritzau 2021).

Drawing on ethnographic fieldwork carried out among both patients and general practitioners (GP) in Denmark between August 2015 and August 2019, our work explores the gap between the discourse of patient empowerment and the practices relating to patients' access to e-health data. During fieldwork, we often experienced how patients, like Hanne above, consulted their GPs to discuss their worries about one or several abnormal numerical records, which they had become aware of through accessing their blood test or X-ray results on the patient portal. Often this led to patients looking up the meaning of the abnormal result online, only to find a variety of possible diseases and conditions likely to be the cause. It is indeed tempting to interpret cases like that of Hanne as testifying how health record transparency empowers patients to take co-responsibility for their health. However, by following patients like Hanne, we learned that health record transparency also serves to confuse patients' intuition about their health status by directing their attention toward the numerical standards as a more valid measure of this than how they actually feel.

Deprived of context, objective numerical measurements are nothing but numbers. Yet, to patients, numbers have an effect on how they experience the world through

their body. When Hanne voiced her worries, the GP explained to her that she should not worry about cancer, since ‘Google tells the least likely and not the most likely’, and as ‘everyone has some numbers that are above or below the reference value’. Hanne’s GP explained further that she needed to undergo a new blood test, which he had already planned to carry out; he was certain, however, that she had ‘nothing to worry about’. He noted that her general state of health was fine and that her liver enzyme was only slightly elevated according to the interval of normality. Hanne appeared comforted by her GP’s explanation and the fact that she would have a new blood test. However, if new tests are taken regularly, one in twenty tests is likely to show that the patient’s enzyme level is positioned at the high or low end of the normal range, although the patient is unlikely to be ill.¹

During fieldwork we discovered how patients’ awareness of numerical abnormality—despite the attempts of medical professionals to explain the diagnostic limitations of test results—continued to puzzle and trouble patients and drew their attention toward the illness potentiality of various vague bodily signs. Scholars have shown how increased public access to numerical expressions of the body elicits a new numerical ontology that prompts people ‘to live by numbers’ (Oxlund 2012) or constructs disembodied ‘individuals on the alert’ (Samerski 2018, 3–4). However, there is also another story to tell about health record transparency—namely, how it also alters patients’ intuition and creates a runaway process of worry and uncertainty.

As argued by Tsoukas (1997), the contemporary information society is founded on the avowed belief of the Enlightenment that ‘the more human beings know, the more able they will be to control their destiny’ (1997, 828). This belief, as argued by Marilyn Strathern (2000), continues to blind individuals who belong to contemporary information societies from seeing what ‘visibility conceals’ (2000, 310). Rather, as we will argue, following Tsoukas (1997), more information may catalyse less understanding and more mistrust. Expanding on Strathern’s and Tsoukas’ work we want to draw attention to what health record transparency may conceal and how the unlocking of ever more numerical records of the body not merely prompts people to live by numbers but enables numbers to direct and change people’s very perception of what health is.

In his book *Angels Fear* (1987), Gregory Bateson argued that the human capacity to sense ‘the sacred’—that is, the greater picture or pattern of a given phenomenon—requires a certain degree of secrecy or non-communication. As an example, Bateson writes that our capacity to form mental images from the multitude of sensorial inputs we experience depends on our ‘faith’ in what our

1 The normality of a blood test is defined within a 95% interval of a normal distribution (a Gaussian normal distribution) and abnormality is defined as the 2.5% below and 2.5% above this interval. In this case, then, one in 20 blood tests will in a statistical random distribution be considered abnormal.

senses tell us, regardless of our lack of knowledge of how our perception has managed to construct these images (ibid.). If we were aware of the processes by which we form mental images, Bateson explains, we would no longer be able to trust them as a basis for action because this communicated knowledge would somehow alter the nature of the processes (Bateson and Bateson 1987, 80; 95–6). We suggest that in contemporary Danish society patients' increased access to numerical records of the body is indeed poised to alter what health is, and how health is perceived.

We argue that the promise of patient empowerment through digital solutions is based on what Bateson termed an 'epistemological error' (1972, 479), and on the false assumption of an ability to 'control' or 'manage' living systems, such as an ecosystem or human health, through quantitative measurements (Harries-Jones 1995, 7). The health status of an individual cannot be fully accessed through a numerical expression or measurement of the body. Such quantities tended to be treated by the patients in our study as if they were analogous to health or illness. The problem with such epistemological errors is, according to Bateson, that they tend to be self-validating and 'pathological' (1972, 480) making the world 'partly become – come to be – how it is imagined' (1979, 205). Bateson lamented how the epistemological error of Western rationality (to view humans as separate from their environment and to focus on parts rather than the whole) had triggered an ecological crisis in which humans are facing their destruction because they have destroyed their environment.

In this article, we suggest that the idea of health record transparency as a path to patient empowerment is founded on an epistemological error. That error triggers the self-validating logic of making people delve ever deeper into the numerical expression of their bodies in order to control their health. We argue that this may have the unintended consequence of entrenching people's experience of their health as disembodied and decontextualised, thus making it increasingly difficult for people to trust both their intuition and the clinical judgement of health professionals. Based on two periods of fieldwork lasting between 12 and 18 months between 2015 and 2019 among patients and GPs in Denmark, we suggest that this disembodiment and decontextualisation is about to trigger a runaway process, whereby well-intentioned initiatives to combat illness and death increasingly come to pose a threat to life itself.

Field site and methods

In 2001, Danske Regioner, the Danish association of county councils and the Ministry of Interior and Health decided to establish the digital portal Sundhed.dk to consolidate relevant information from all parts of the healthcare system and

establish an electronic gateway for citizens and healthcare providers alike (Sundhed 2019). The site serves as a unified digital health portal, providing citizens and health professionals access to and information about national health services; information on health, diseases, and treatments; and easy access to personal health data. Although now an established part of Denmark's digitised health services, use of the platform is voluntary for patients, who can opt instead to have their test results delivered through a consultation with a relevant healthcare professional. The official aims of the e-health portal are to bring together relevant information from all parts of the health service, to offer a shared platform for communication, to provide healthcare providers with easy access to clinical information about their patients' medical histories, and to empower patients by offering maximum insight into and transparency within the healthcare sector (Sundhed 2019).

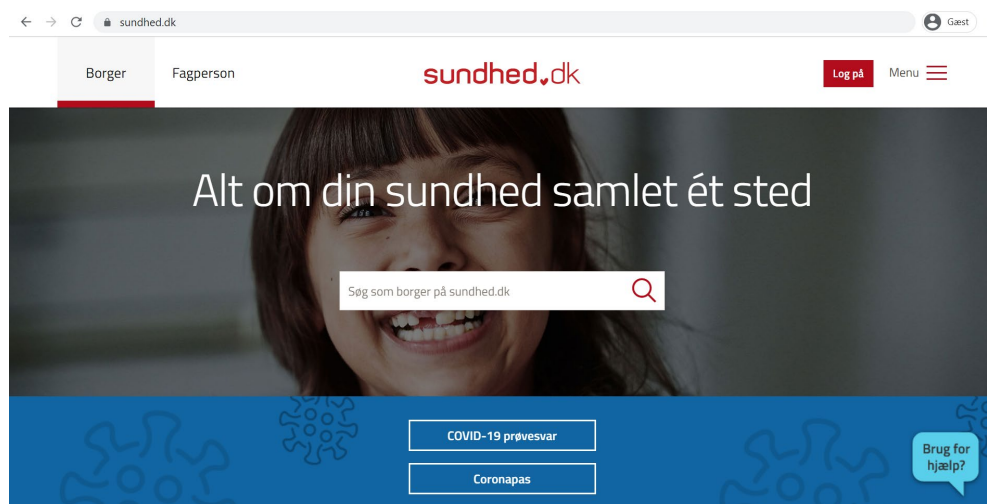


Figure 2. Front page on Sundhed.dk. The headline reads: 'Everything about your health in one place'. Source: www.sundhed.dk.

Since its launch in 2003, the national health authorities have made a number of expansions to the platform to include new e-health technologies. These include: the Danish National Health Data Network; the National Prescription Server; the e-journal *Shared Medication Record*; and the electronic Health Care Record (Jensen and Thorseng 2017; Kierkegaard 2013). The last of these [*sundhedsjournalen* in Danish] was implemented in 2013 to grant citizens and health professionals easy access to health data from all parts of the health system. Its aim is to empower patients to become actively engaged in their health and treatment and to strengthen the cooperation between citizens and health professionals (Sundhed 2019).

During our research into diagnostic processes and patients' experiences of illness, symptoms, tests, and treatments, we observed randomly selected consultations

during the course of 24 full-day observations in six general practices located in the Zealand Region, in the south of Denmark. Here, we became aware of the pivotal role that access to numerical test results played in patients' interpretation of symptoms and perception of their health. To investigate this further, Kristensen conducted interviews with both patients and GPs, to explore how information from the e-health portal influenced perceptions and decisions regarding diagnosis and treatments. In addition, we draw on Jønsson's fieldwork among 14 older people with multiple chronic conditions, which included in-depth interviews which took place over an extended period of time and informal conversations regarding numerical abnormalities and e-health.

The research project from which this article proceeds is part of Brodersen's research group on overdiagnosis, which focuses on the theme of self-testing and screening, exploring test sensitivity and specificity, predictive values, informed consent, and what the psychosocial consequences are for healthy people when they receive abnormal test results. The University of Copenhagen and Region Zealand approved the studies that contribute to this project, and all data were handled and kept in accordance with the rules of the Danish Data Protection Agency. All participants provided oral informed consent, and all recorded interviews were transcribed verbatim and coded together with field notes from observations and other relevant material. The themes arising from the data were discussed among the authors and in the wider research group and presented at national and international conferences. All interlocutors were given the opportunity to read this article and to respond and comment, but all declined because of lack of time (GPs) or lack of time and energy (patients).

Patient empowerment through e-health transparency

Flexible digital healthcare infrastructure and patients' freedom to access their health data from any digital device are often portrayed as an important means to ensure patients are empowered. Policymakers commonly portray Denmark as world-leading when it comes to the development of patient-centred e-health solutions at the national level, and present the Sundhed.dk portal as an example of how health record transparency can empower patients to manage their health and wellbeing (Petersen 2019). The English journalist Helen Russell even singles out health record transparency as one of the secrets behind 'Danish happiness'—along with a good work–life balance, a comfortable home environment, and cycling (Russell 2016). This is a point also affirmed by Sundhed.dk's Chief Executive Officer Morten Elbæk Petersen who, in an interview with Russell, states: 'patients who are well-prepared and feel co-responsible and invested in their health feel happier and healthier' (ibid.).

Quantitative surveys, indeed, and as commonly argued by national and international policymakers and health authorities, appear to testify that e-health provision in Denmark has fulfilled these goals. A national survey conducted in 2018 shows that on a monthly basis 1.8 million unique visitors used Sundhed.dk and that the feature most accessed by citizens was the electronic Health Care Record, used by approximately 400,000 citizens per month over the course of 2018 (Sundhed 2019). The survey also reveals that Danish citizens and health professionals feel that the electronic medical record has made it easier for patients to find relevant health information, granted them a better overview of their health or illness, and has strengthened citizens' sense of patient security and safety (ibid.).

However, the challenge of health record transparency is, we argue, that access to paraclinical test results may create unnecessary worries among patients because they are often unaware that an abnormal test result is not always a sign of disease and may instead reflect a normal or non-pathological condition. Paraclinical test results are constituted as working tools for medical professionals, whose task it is to interpret these results in combination with the consultation of a broad area of other diagnostic factors, such as the patient's current circumstances and medical history and findings from a clinical physical examination. Test results are often abstracted numerical standards which have been quantitatively evaluated as either normal or abnormal through means of comparison with an individual number or value, a reference interval being based on statistical ranges found in healthy people (Katayev, Balciza, and Seccombe 2010). As Hanne's statement in the introduction reveals, when patients access their test results they commonly interpret them as unambiguous, meaning they tend to read an abnormal test result as a sign of the presence of illness, and a normal test result as a sign of its absence.

Following this, some medical professionals in Denmark, as elsewhere in the Global North, continue to argue that health record transparency gives patients access to information that is unclear to them, causing undue worries and anxiety (Grünloh, Cajander, and Myreteg 2016). Although Danish health authorities acknowledge that health record transparency may spark unnecessary worries among some patients, they maintain that such worries are transitory, as patients become better equipped to discuss their worries when empowered through health record transparency. We do not dispute that health record transparency may give patients a feeling of being more in control of their health and may grant some patients valuable insights enabling them to better manage their health. Nonetheless, we argue that, at least to some degree, the sense of control that patients experience is fictitious—and simply a reflection of the self-validating logic created by the

epistemological error of seeing healthcare transparency as a means of controlling personal health.

The tyranny of abnormal numbers

Lise laughed apologetically when she told me about her worries about cancer: ‘I am only 38 and I never smoked so I know it is unlikely that I have lung cancer. But still, when I cough or feel ill the thought of cancer is lurking.’ Lise then explained that her worries about lung cancer had started when she had checked her blood test result on Sundhed.dk and discovered that her vitamin B12 level was a little bit higher than the normal level. She told me how she had initially thought that this was a good sign, since ‘everyone knows that vitamins are good for the body’. Yet out of curiosity she had discovered by googling that people with high levels of B12 are at greater risk of lung cancer. This had prompted Lise to call her doctor, who explained that she did not have to worry about cancer, as her B12 level was only slightly higher than the average number and that, being a non-smoker and having no other signs of cancer, she was highly unlikely to be seriously ill. Lise acknowledged that as she generally felt well, she was convinced that her GP was right. Yet she explained that the thought of cancer sometimes reappeared when she had a cold or had been coughing for a few days.

The story of Lise is not unique. On the contrary, we encountered many similar stories during our fieldwork in general practice and among patients. Our data show how the very awareness of an abnormal blood test, despite medical professionals’ attempts to reassure patients of its probably benign nature, frequently continues to—in Lise’s words—‘lurk’ in their minds, drawing patients’ attention toward the disease potentiality of various vague bodily signs. We view paraclinical test results as being, as Lock and Nguyen (2010, 18) have termed them, ‘technophenomena’, indistinguishable from the technologies that produce them, but which nevertheless act as ‘technologies of the self’, modifying and shaping embodied experience.

Danish anthropologist Bjarke Oxlund (2012) argues that increased access to numerical records of the body has given rise to a numerical ontology among senior citizens in Denmark, who increasingly experience their health through numerical expressions of the body. Oxlund’s interlocutors tend to communicate about their health almost exclusively in numbers, a phenomenon partly prompted by the large-scale availability of low-cost technologies such as scales and blood pressure meters in tandem with the equipment and scanners used by healthcare professionals (*idem*, 17). Building on Oxlund, we argue that health record transparency does not merely contribute to the emergence of a numerical ontology but perhaps more appropriately what we—inspired by Jacques Derrida’s (1994) work—may term a ‘numerical hauntology’. Derrida introduced the term

'hauntology' to draw attention to the ghostly aspect of the ontological, namely how every ontology (the historical perception of what is) is inevitably haunted by its finitude; in other words, it is haunted by that for which it cannot account (ibid.). Lise did indeed know that it was highly unlikely that her slightly high B12 level was caused by lung cancer. However, as her GP could not quite account for why this level was high, and unable to explain it except in statistical terms, the thought of cancer somehow persisted.

The challenge of patients' access to numerical records of the body is not merely that it turns their attention toward the illness-potentiality of the normal, as in the case of Lise, but also that it may distance patients from the illness potentiality of the abnormal. This is evident in the case of Grete, a 67-year-old woman working in retail, who over the course of a year had undergone several investigations for cancer at the hospital. It had all started the previous winter, where Grete had noticed that she had lost 'a little bit of weight'. At first, she did not worry about it. However, several customers asked Grete whether she was ill, having noticed that she had lost weight, and when Grete weighed herself she realised that she had lost five kilograms in a couple of months. Although she felt a bit concerned, Grete did not consult her GP as she thought 'it was probably nothing to worry about'. However, after a couple more weeks, Grete checked her weight again and realised that she had lost two more kilos. Subsequently, Grete consulted her GP, Mads, who found her weight loss concerning, and referred her to a cancer pathway.

While pouring coffee Grete said, in a tired tone of voice, 'I have been through so many tests. But they did not find anything ... they did not find any cancer, and that is of course good'. However, what the doctors did find as Grete went through the cancer pathway (the specific name of which Grete was not quite sure), was that Grete's blood contained something they described as an 'M spike'. 'But I do not care about that M spike', Grete confided, relaying that her GP had explained to her that her M spike was of a rather low number, meaning that she had a 'quiet cancer'. 'This means that I can live and die with it, as it is unlikely to become active cancer', Grete explained. Asked whether it was a relief that the investigations had not detected any cancer, Grete responded with a rather irritated look and said in a loud voice, 'I *have* cancer. I have an M spike and it cannot be cured'. When asked, 'but it is quiet, I mean an inactive cancer, isn't it?' Grete answered, 'Yes, my GP keeps on saying this. But when I look at the results of the blood test, I can see that the numbers have risen, and then, of course, I start to worry whether it is inactive or not'. Grete then explained that she had booked the GP consultation in which she had first become part of our research because she had discovered that she had blood in her stool. She explained that she had ignored it at first because she thought she had already been through so many tests that it was probably nothing to worry about. However, her husband had insisted that she called the doctor,

telling her that ‘even an idiot knows that one has to consult the doctor if there is blood in the stool’.

While she had not been particularly concerned about her weight loss, seeing abnormal test results (the identification of the M spike) had elicited a runaway or cascade effect. Somehow, Grete was paradoxically made both more aware of various vague bodily signs, which she interpreted as testimony of her M spike having turned into an ‘active cancer’, and less concerned with alarming bodily signs, such as blood in her stool. Grete’s case reveals the opacity of transparency, namely how access to an abnormal numerical record of the body may blur more than it reveals. The case shows how numerical records of the body steer the patient’s intuition, making it increasingly difficult for people to distinguish between normal and potentially pathological bodily signs.

The tyranny of normal numbers

The contemporary focus on early detection of disease and public health interventions such as screening programmes, health awareness campaigns, as well as the categorisation of risk groups, risk behaviours, and pre-disease states, teaches patients to check on their health not only when they feel unwell. As a result, citizens increasingly turn to screening programmes and health check-ups for reassurance, even though screening programmes regularly ‘turn indolent pathology into illness’ (Brodersen, Schwartz, and Woloshin 2014), which results in unnecessary treatment (overtreatment) and may inflict physical as well as emotional harm.

The case of 64-year-old Johnny exemplifies how the unearthing of normal numerical records of the body through health check-ups may grant patients an illusion of certainty: ‘I have worked with chemicals, so due to that the thought of cancer is always lurking. So I am trying to have regular health check-ups. And not long ago, I went to have a health check-up, I had some blood tests and an X-ray of my lung. And everything was fine’, he explained with a smile. He then elaborated on how he had not felt well lately, though he could not quite pinpoint it. But, as he said, ‘now I feel much better, you know, you feel better, because everything was normal, and well, then you know, that it is not today you have to say goodbye to friends and family. There is still time. Well, that service check-up, it calmed me.’

However, Christina, a 42-year-old GP, explained how such a numerical approach to health may blur more than it reveals:

Since that campaign last year ... the one telling that men never consult the doctor, a rather large number of men have presented asking me for a health check-up. They present without symptoms or anything, and they engage that

device fault model. You know, they say I have come to have a 50,000-kilometre service ... but it [health] is not like switching the motor as you would do at the auto repair shop, and then it can tell that all systems: check, check, check, it is working just fine. They believe everything is measurable. But that is exactly the point, everything is not measurable here.

The belief that 'everything is measurable' captures the epistemological error of contemporary times. During fieldwork, we found that it was frequently easier for patients to subscribe to the idea that a normal blood test is not analogous to being well than for them to trust that they were well despite having had one or several test results outside the normal range.

Runaway processes of measuring and testing

The rapid development and progress of technology today enables the medico-technology sector to invent increasingly more sensitive biomarkers in blood tests and high-resolution imaging tests, eliciting a growing volume of numerical records from different parts of the body. The limits of a paraclinical test result are, however, that they do not provide the complete clinical picture of a person's health. Paraclinical test results are the outcome of the measurement of large quantities of datasets at the population level, meaning that on a regular basis some healthy people will inevitably receive test results that are flagged as abnormal, just as some ill people will have results flagged as normal. The fallacy arises if people, as instructed by public health policy, make efforts to control their health through monitoring numerical records of the body.

Several of the GPs we followed during our fieldwork voiced concerns about how patients' free access to test results elicited unnecessary worries among them. Sixty-two-year old GP Mads explained:

Earlier the patients did not see when the numbers were slightly abnormal, we just shouldered it. I mean, in medicine you can never be absolutely certain. It is not an exact science, but it is our task to shoulder that it is fine, if we believe it is fine. Now they have access to their test results and they often turn worried. When I started twenty years ago, we [physicians] also got test results on all kinds of irrelevant things, though we had only ordered the blood tests to check certain things. However, it just confused people, it became more difficult to diagnose. Hence, today, we only get the test results of what we ordered, though the machine may still elicit numerous test results.

Mads explains how more information does not automatically broaden understanding and how less information may actually fuel more understanding. The challenge of health record transparency is not merely that patients' access to

medical test results may breed epistemological errors, but that the repetition of such errors may elicit what Bateson (1972) has termed 'a runaway process', namely a self-reinforcing process, which compounds rather than solves the problem it was intended to resolve.

An example of one such runaway process is elicited through the identification of abnormal numbers in the use of a prostate specific antigen (PSA) blood test among men with no symptoms of prostate cancer (Mukai et al. 2010). Medical studies have shown that the PSA test is indeed effective in diagnosing prostate cancer. However, the limits of the test are that what it mainly picks up are cancers that are unlikely to cause any harm (ibid.). To have a positive PSA test might mean men unnecessarily living with the stigma of having cancer and the side effects of unnecessary treatment, such as incontinence and erectile dysfunction (Nielsen et al. 2020). This argument was confirmed when we met Eric, a 70-year-old retired sailor, who had been diagnosed with prostate cancer ten years earlier. In the presence of other people, Eric is usually a man of few words, but during our visits he shared his concerns. When diagnosed, he had been told that he might live ten years with prostate cancer, but later the doctor had corrected himself and added that it might be as long as 20 years. Eric continues to go for regular check-ups, and even though the cancer is not developing, he suffers from both impotence and anxiety as side effects of his treatment and of the mere thought of having cancer and the decrease in the remaining expected years of his life. The latter he seeks to control by meticulously following his numbers and test results on Sundhed.dk. He said: 'It is supposed to be between 0 and 4', adding, 'It's been going well, it's been on 1.1 so now I only have to go every six months and get an injection in my stomach. It works.' Eric, unable to explain what 'it' is or how it is measured, clings to the numerical value as an explanatory model, thus making sense of what he cannot sense in his body. Rather than trusting his intuition and relying on his lack of symptoms, Eric is constantly looking for new numbers to explain his condition, and new tests to provide reassurance that he is not going to die soon.

Bateson (1972) described such runaway processes in phenomena as diverse as gang violence, armaments races, and environmental destruction, where forms of growth, which are meaningful in the short run, eventually turn out to be harmful. On the latter, he elaborates: 'When you have an effective enough technology so that you can really act upon your epistemological errors and can create havoc in the world in which you live, then the errors become lethal. Epistemological error is all right, it's fine, up to the point at which you create around yourself a universe in which that error becomes immanent in monstrous changes of the universe that you have created and now try to live in' (idem, 461).

Discussing the runaway process in the context of the future of medicine amid biotechnological progress, GP Mads shared that:

The nightmare is that we start to test everyone genetically. And then we start to remove the different body parts, where we according to the genetic test may develop cancer. And then we may not be able to breathe anymore, because we remove the lungs, too bad ... but there could be cancer in the lungs. I'm joking, but seriously this is what happens if we expect total certainty.

Expected certainty is an important characteristic of the illusion of measuring and testing. What renders quantification so seductive is the capacity of numbers to act as 'truth-bearers' and to provide knowledge about phenomena that are often highly complex and opaque. Thus, we attempt to control medical uncertainty in a way that, as Adams and colleagues have put it, governs the present as if the future is what matters most (Adams, Murphy, and Clark 2009, 248). The question remaining is whether patients' access to test results will empower them to better manage their own lives and health or whether it will empower them to petition for more tests, eliciting a cascade effect or runaway process which 'branch[es] out like a rooted parasite through the tissues of life' (Bateson 1972, 489).

The problem with carrying serious epistemological errors is, as argued by Bateson, that they tend to 'stick' like honey: once there, the falsification spreads and any attempt to wipe it off will only result in spreading it further rather than eliminating it (idem., 479). The sticky effect of inconclusive numbers is reflected in what Deyo (2002) terms 'the cascade effects' of biotechnologies, namely that inconclusive test results or incidental findings often elicit a snowball effect of further testing, which may subject patients to unnecessary anxiety and treatment. In a similar vein, Sah, Elias, and Ariely (2013) have shown how inconclusive test results can lead to an 'investigation momentum', triggering patients' requests for further testing in their 'relentless pursuit to resolve uncertainty'. As Gitte Meyer and colleagues have noted, the challenge of risk assessment exercises such as those involved in evaluating a paraclinical test result is that 'scientific uncertainty is turned into risk' (Meyer et al. 2005, 235). For them, this risk cannot 'be totally ruled out after mobilization' (idem., 238) and this therefore creates a runaway process of measuring and testing.

Abnormal numbers appear to mobilise their ghostly effects, where 'that which appears to be not there becomes a seething presence' (Gordon 1997, 8), manifesting itself in the lurking thoughts of: 'what if I am ill?' Consequently, patients' requests for health check-ups and tests accelerates in a quest for certainty. This often mobilises new uncertainties, entangling people in a ghostly runaway process fuelled by the illusion of transparency as a means of gaining control over life and death—but which somehow, paradoxically, labels more and

more well people as potentially unwell. Yet, as we have argued, even ‘normal’ numbers spark uncertainty as to whether to doubt those numbers or question embodied experiences.

Transparency altering clinical conversations

We certainly acknowledge that digital access to patient health records ensures flexibility, since patients no longer have to call the doctor or be present in the clinic to gain access to their test results. However, the tricky thing about flexibility is, as Bateson argued, that flexibility gained in one domain tends to reduce the flexibility of other domains. Bateson defines flexibility ‘as an uncommitted potential for change’ (1972, 497). This is an essential quality for living systems: be it an ecosystem, a living organism—or, as in our case, the health of a human being in particular and the health system in general—such systems are capable of continually adapting to changing circumstances. Bateson and Bateson argue that upholding the flexibility of any living system requires that certain information within the system be kept unknown (1987, 86) in order to preserve alternative interpretations. Thus, the flexibility of health record transparency enabling patients the freedom to access their medical test results anywhere in the world may somehow paradoxically add to the decades of disconnection patients have felt from institutions, freezing their interpretation skills and making the system less flexible.

Scientific progress such as e-health record transparency has turned people into ‘somatic individuals’ who are given responsibility for managing and monitoring their health, causing an exaggerated focus on risk and disease control (Petersen and Lupton 1996). In the Danish context studied, this has resulted in uncertainty and an ambiguity between bodily sensations and symptoms of illness (Offersen et al. 2016). It has also added to the ‘deconstruction of mortality’ (Bauman 1992, 131), translating the inevitable death into particular health and disease problems that are ‘preventable’ (idem., 130). We find health record transparency to provide just some of the nuances in the palette of issues, discourses, and phenomena that induce health anxiety, and we argue that transparency furthermore has the potential to steer conversations in clinical encounters.

As we have shown, the revelation of numbers to patients through Sundhed.dk does not necessarily lead to control, but it may cast the conversation in clinical encounters in a new numerical language of the expression of health anxieties, uncertainty, and doubt. Transparency of numerical records of the body comes with an illusion of certainty: the test results indicate that something is wrong or that everything is fine, which runs counter to a flexible interpretation of how it is that a patient feels; this illusion of certainty shapes the conversation that takes place

between a GP and their patient. GP Christina, for instance, puts great effort into explaining to her patients the limits and benefits of test results when they enter her consultation room with concerns about a number they have seen. She explained:

Often, they [the patients] call me to ask for the result of a blood test [that] one of the other GPs has ordered. Then I tell them that I do not really know what the issue is, so I can simply tell you that the blood tests are normal. Then they will answer: 'Great, then everything is fine'. Then I tell them that a normal blood test does not necessarily mean that everything is OK. I tell them that they need to speak to the doctor who ordered the tests ... And then I explain that a human being is like a piece of art. When you look at certain spots of a human being, it is like looking at a piece of art through a kitchen roll and blood tests [are the] equivalent to placing the kitchen roll at ten different spots on the piece of art. It may be that you have seen ten spots of the piece of art and that you have an idea, that, okay, those spots look normal, where I looked, but there may be huge gaps, just next to the spot, where you placed the kitchen roll. And this they do understand.

As Bateson (1972) argued, the healthy persistence of any living system requires that information peculiar to certain parts of the system should not be communicated to other parts of the system. Our very capability to sense the greater picture of a given phenomenon requires a particular kind of knowledge that focuses on details rather than the larger picture, and enables us to be responsive to 'the pattern which connects' and constitutes the whole.

In the wake of the accessibility of e-health records, numbers are playing an even more significant role in clinical encounters. Peter, a 47-year-old GP, stressed that the challenge is growing even bigger with the advent of new self-measurement technologies: 'there are no regulations; otherwise healthy people book consultations based on some random numbers, which even if they are accurate have little to no significance for the person's life!'

The challenges of self-measurement have already been aptly discussed (see Lupton 2016), yet the argument that self-tracking as an approach to control, manage, and regulate (ibid., 51) applies also to health-related numbers in general. In American writer Gary Wolf's words: 'we tolerate the pathologies of quantification – a dry, abstract, mechanical type of knowledge – because the results are so powerful. Numbering things allows tests, comparisons, experiments. Numbers make the problem less resonant emotionally but more tractable intellectually' (Wolf 2010). As theorised by anthropologist Vincanne Adams, numbers are always made meaningful through stories, and hence numbers are never neutral because particular pandemic logics and metrics can be mobilised in different places to wildly different effects (Adams 2016). We see this in the non-contextuality that numbers

and metrics attain when they are used in different settings and the following different effects that they have. With health record transparency, numbers read on Sundhed.dk at home may render different reactions than when the same results are explained in the clinical consultation. Karina, a 38-year-old GP, was concerned that patients' access to test results bred unnecessary worries:

It creates a lot of worries and typically it is triggered by a slightly abnormal blood test, which does not mean anything, but still, it makes people unnecessary worried and then they consult Doctor Google, and then it all starts. If you have a headache, you have a brain tumour or that, and so it goes on and on ... They are not capable of judging a blood test. It is even difficult for our staff [nurses and secretaries] to interpret the blood test and they are working with it daily. And it means that people who are well may feel that they are ill or feel that they suffer from some malignancy, although they do not. Of course, we take time to explain [this to] them, but at times it can be difficult to convince them.

Although medicine is commonly termed a science, it is not an exact science because, as argued by Kathryn Montgomery, 'the unavoidable reality of its practice is the uncertainty of applying general rules to particular patients' (2005, 133). As noted by the physician Francis Peabody in 1927, 'the clinical picture is not just a photograph of a man sick in bed, it is an impressionistic painting of the patient surrounded by his home, his work, his relations, his friends, his joys, sorrows, hopes and fears' ([1927] 1985, 878). Clinical reasoning is, as argued by Montgomery, the conjunction of art and science: that is, 'the rational, clinically experienced, and scientifically informed care of sick people', which 'enables physicians to fit their knowledge and experience to the circumstances of each patient' (2005, 33). Clinical judgement is thus a matter of constructing an overall picture by going beyond the momentary clinical snapshot of the patient's condition through exploring the broader patterns with which it connects.

According to both Karina and Mads (the GPs we followed), it is difficult for most patients to judge medical test results because they view test results as isolated facts and not as relative to other clinical factors. In some cases, as Karina elaborated, blood tests may of course be 'the divine truth' and unambiguously point toward a specific malignancy or serious disease in general. However, in most cases blood tests only provide what Karina termed a 'partial picture', which ought to be seen within the overall clinical picture.

Karina told us that she always made efforts to explain to people why they did not have to worry about a slightly abnormal test result, and how she tried to recount and clarify the causation behind her judgement—for instance by elaborating on how the numerical record was not alarming when considered alongside the

patient's general state of health and way of living. Nevertheless, Karina said, 'the most important [thing] is still that they trust me when I say that it does not mean anything. I hope they believe me when I say ... I mean I hope I manage to expel their anxieties'.

Historian Theodore Porter (1996) showed that throughout the 20th century external pressures to regulate medical practices and internal disagreements within the medical community have initiated a shift from trust in medical expertise towards trust in numerical standards and quantification. The possibility of death and suffering from disease is a constant presence in human existence but may turn to fear when fuelled, for instance, by family history of disease or internet research precipitated by an abnormal test result. As we have shown, each of our interlocutor patients has had difficulties in trusting that they were well according to their own bodily sensations, such as a lack of symptoms, if biotechnologically produced numbers from a test indicated otherwise.

In the social sciences, trust may both be a strategy as a deliberate, conscious, and rational choice, or an attitude or affect that serves psychological or social purposes (Bruun, Hojer, and Mannov 2020). An attitude or affect can also, as we will argue is the case in health record transparency, function as a strategy: a rational choice in the situation of uncertainty about whether or not one may be ill, where trust in numbers appears to be functional and prudent. According to Bateson, trust or faith is what enables us to trust our own image-making processes, believing that the pattern the doctor describes resonates with our own experience of our health. Trust or faith also defends us from doubts by virtue of us being unaware of the gaps (1987, 95) which are characteristic of all knowledge (in other words: while I feel well, the abnormal number could still be a sign of disease). In our data, transparency can lead to mistrust more in terms of 'what if' questions rather than mistrust in the GP. Thus, accessing healthcare records directly may be one of many triggers for distrust by transferring, as it does, the responsibility to the patient under the guise of 'empowerment'. Despite the GPs' attempts to calm patients down, explaining that what they had seen on Sundhed.dk is not necessarily alarming, it may be that health record transparency is rather a lens for understanding how patients—and professionals—come to live with uncertainty. The question is then whether transparency can expel the secrecy of the medical profession, or whether scientific numbers still hold a kind of magic.

The magic of the science of revelation

Today, the development of ever more sensitive biotechnologies, from digital imaging technologies to liquid biopsies, makes it possible to gaze ever deeper into the hidden organic interior of the human body and reveal what was for long

revealed only to the medical gaze, such as cancer at a very localised stage and genetically established cancer risks. In Denmark, as elsewhere in the Global North, the media abounds with stories about the promises such new technologies hold. In the last couple of years, headlines in the Scandinavian public media have read: 'Find cancer in time – a blood test can reveal everything' (BT 2009) and 'Your blood reveals cancer risks' (DR 2018), to name but two.

The promises made by new biotechnologies to detect cancer spark new hopes among the public that cancer may be cured if detected early, but also generate new fears and uncertainties, drawing people's attention toward the concealed cancer potentiality of the apparently well human body. Thus we might describe the patient e-health portal as a technology of anticipation in the sense developed by Adams, Murphy, and Clark (2009). As an attempt to predict and foreclose uncertainties, anticipation is a way of actively orientating ourselves towards the future. To explore this, let us examine one consultation with the GP Peter. Tobias, a 23-year-old man, entered his consultation with a worried look written across his face. In the last couple of weeks, Tobias had presented several times at the general practice with vomiting, nausea, and stomachache. As Peter had already questioned and examined Tobias thoroughly and conducted several tests for infection and diabetes, and as Peter knew that Tobias' stomachache had started following a holiday in Greece, Peter ascribed it to a benign viral infection. Although Tobias felt that his condition had improved, as he had stopped vomiting, he had decided to consult Peter again. He still had 'some stomach pain and nausea', which worried him, because he had realised that he quite often suffered from stomach pain. Peter asked Tobias what his thoughts were about the cause of his stomach pain. 'I am not sure', he replied, 'maybe I am allergic to milk or maybe it could be a sexually transmitted disease? I would like you to check me for everything.' Peter explained that if it was gonorrhoea or syphilis there would be sores on the genitals. Tobias answered, 'I don't have sores, but I would like to have some blood tests, just for reassurance. I also have some erectile dysfunction—can it be due to a serious disease? I have read on the internet that it can be due to cancer, and you can see that in a blood test, can't you?'

During fieldwork, we often met patients like Tobias, who have read about cancer on the internet or in a newspaper and requested a blood test to uncover whether various vague bodily signs could be due to cancer. For a long time, cancer was what Michael Taussig (1999) has termed a 'public secret', denoting 'something that is known by everyone, but not easily articulable' (216). Today, the secrets of cancer are gradually being unveiled through scientific progress, and yet the mystique surrounding cancer appears not to be decreasing, but simply to have been deferred to the general public, capturing people like Tobias, who exists in a state of alertness as to whether the non-cancerous body may conceal cancer.

The very act of revealing the mystery behind a public secret, as Taussig has argued, has the result that ‘the mystery revealed may become even more mysterious’; the fact that it has been concealed reveals it as something powerful, something which is ordinarily concealed (Taussig 1999, 3). Taussig (2016) also argues that the dialectic between revelation and concealment elicited through the unmasking of a public secret resembles that of magic: namely that the mystery is heightened, not dissipated, by unmasking. Perhaps it is the case that biotechnologies, precisely due to their promises to unearth the secrets of the body, embody a kind of magic, because they ‘bring inside-outside, unearthing knowledge and revealing mystery’ (Taussig 1999, 3).

Patients like Tobias appear to be captured in the contemporary magic of biotechnological revelation and its capability of unveiling cancer at ever earlier stages. To Tobias, this paradoxically also re-mythologises cancer by confirming the perception that, despite doctors’ attempts at reassurance, something may indeed be hiding in the interior of the apparently well human body. Bateson (1972) argued that a certain degree of secrecy and unknowing is pivotal if we are to maintain our knowledge of the whole, namely our capacity to sense the overall pattern of a phenomenon, which may be destroyed through the revelation of concealed information. Still, as aptly argued by Manderson and colleagues (2015), the revelation of a secret is a mode of forming a relationship. In our research, the exposure by GPs of general uncertainty in numerical test results indeed built an interpersonal relation between patient and physician by releasing patients from mistrust and reassuring them, at least for a while, that they are not ill. Disclosing secrets (or a series of secrets) is an act that is, nonetheless, orchestrated by the State (through its provision of the e-health platform) and is an instrumental and tactical action in which the State inscribes a particular version of one’s life—in this instance, health status—onto the citizen. This act forms a trusting relation that the State knows the truth about your body and is now sharing it with you (Manderson et al. 2015). Previously, the State sought to increase the superiority of the professionally informed by keeping their knowledge secret (Weber 1947, 233). The notion of transparency promises to end that secrecy, but real transparency has yet to materialise, and the growing instances of firewalls being used to protect health data demonstrates that secrecy is instead being displaced. Firewalls, together with the two-step authentication required when a user enters her personal site on Sundhed.dk also serve to remind the patient that this is crucial information, that these numbers are powerful. Hence, the social-material relations that underpin digital disclosures suggest that they function to reconfigure visibilities of power rather than reveal extant secrecy. In other words, it is how transparency and secrecy are enacted that enables Bateson’s (1972) necessary level of unknowing in a skilled movement back and forth between revelation (transparency) and concealment (secrecy).

Conclusion

We have shown how the granting of access to patients of their test results by e-health solutions may not only create the patient empowerment that is intended but also spark worries in patients and thus alter their perception of and intuition about their body, driving clinical conversations with GPs. It is, however, important to note that patient worries are not only created through health record transparency but from a broader societal discourse, news reports, Google results, and public health campaigns. In that regard, it is not just the numbers by themselves, but also family history and self-perception of health that may influence people's health-seeking behaviours and health anxieties.

In this article, we have focused on the immediate opacity of both normal and abnormal numbers in relation to a standard reference point and how transparency may trigger a runaway process in which numerical values—be they normal or abnormal—transform into a threat to life itself. As such, our ethnography supports the intricate contradiction between trust in biomedical sciences and the uncertainty in testing, diagnosing, and treating. In particular, our ethnography demonstrates how patients' access to all test results adds to the quest for certainty, which can never be fully obtained; instead, its pursuit mobilises new uncertainties. Hence, patients can become trapped in a ghostly (Gordon 1997) runaway process fuelled by the illusion of transparency as a means by which to gain control over life and death. Paradoxically, as shown in this article, even 'normal' numbers make patients worry that they may still be seriously ill, as their reasoning for being unwell has become disembodied and transformed into interpretable numbers, creating worries that one might be suffering from a life-threatening disease.

Our message is to pay attention not only to the patient empowerment side of e-health transparency, but also to how citizens' and patients' increased access to numerical records of the body are altering perceptions of health and afflicting people with worries and insecurities. We have proposed an understanding of this in light of Bateson's seminal work which, although set amidst other areas of life, functions as a critical lens for understanding contemporary challenges in healthcare. We encourage scholars of social science to focus their attention on how numbers operate in citizens' and patients' everyday lives and on what they represent and how they function alongside the professional clinical standards that are inextricably bound into the healthcare system. Such a study reveals how the authority of expert knowledge or bodily experience can, as for instance in this case in the name of transparency and empowerment, be undermined.

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