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Data sense-making and communicative gaps on sundhed.dk

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Abstract

This paper examines personal experiences of digital health data on the Danish eHealth platform sundhed.dk. Taking a patient's view, the paper understands data sense-making as an embodied communicative practice. The empirical analysis, consisting of 24 purposefully sampled interviews, is brought together with the conceptual framework describing and unpacking the ambivalences to be found in digital health data experiences into themes of data ambivalence, emotional ambivalence, communicative ambivalence and identity ambivalence. This in-depth empirical description of patients' ambivalent experiences contributes to a more nuanced understanding of the profound changes digital health data is having on a patients' everyday lives. In particular, it emphasizes the communicative challenges arising from the constant availability of digital health data anytime, anywhere, and calls for further research into the new and unfamiliar communicative situations in which patients are placed and forced to navigate in.

Keywords

digital health, data, patient experiences, ambivalence, communication, eHealth

Introduction

Patients increasingly have access to their digital health data. In Denmark, several digital platforms and applications allow patients to become part of the public health care system: from checking laboratory results to reading a doctor's note and accessing more general information about health-related issues. Sundhed.dk (the word "sundhed" is Danish for health) is one of the most used digital health platforms in Denmark, with 3.6 million unique logins in 2020 (Sundhed.dk's annual report, 2020). According to sundhed.dk, the number of users doubled during the Covid-19 pandemic. One of the reasons for this is that sundhed.dk is one of the central access points for Covid-19 test results. As checking Covid-19 test results became an almost daily routine, engaging in digital health data has also become a more integrated practice in everyday life. More and more Danish citizens are using the platform to obtain an overview of their medical records and learn more about their health status (Danmarks Statistik, 2020).

Sundhed.dk was established in 2001 in order to make use of the potential digital technologies have to offer, thus creating a platform where all health information and communication is collected in a central place. While, in the beginning, the focus lay purely on citizens' accessing their health data, today "the citizen as an active participant" is the most important strategic priority (Strategy sundhed.dk, 2023). This means that access to one's health information and general knowledge about one's health status ideally help and support citizens to create and maintain a healthy lifestyle, and further allow them to become competent partners in the public health care system.

Current research related to the medical field has been studying digital health technologies, primarily from a technological perspective, examining opportunities and challenges as well as structural effects (Fisher & Britten, 1993; Fisher et al., 2009; Woods et al., 2013). Critical social research, focusing on the societal impact of digital health technologies, states that researchers are only at the beginning to recognize the major implications such technologies have on contemporary society and in patients' everyday lives (Lupton, 2016; Pink et al., 2017). The aim of this research is to examine patients' personal experiences of digital health data, illustrating to the arising communication situation patients are entering. We particularly want to attend to how feelings of empowerment, independence, perplexity and doubt intermingle when trying to make sense of digital health data.

In theoretical terms, we expand Lupton's concept of data sense-making (2018) by connecting it to Peter's (1994) idea of communicative gaps as constitutive of all communication processes, understanding data sense-making as an embodied communicative practice. We further draw on the concept of assemblage, pointing towards the complex layers in patients' experiences and interpretations of their digital health data. The empirical analysis, consisting of 24 purposefully sampled interviews, is brought together with a conceptual framework unpacking the ambivalences found in patient experiences of digital health data. Before elaborating on the theoretical framework and presenting the empirical analysis, in the following, we briefly describe the Danish context as a backdrop

to this study. We start by giving a short introduction to Denmark as a highly digitalized country followed by a general overview of the developments of eHealth in Denmark.

Public health care and eHealth in Denmark

Denmark is a highly digitalized country with high trust rates in public institutions (Svensen, 2018), and it has been ranked top in the European Digital Economy and Society Index (European Commission, 2022) for several years in a row. Recently, though, the Danish public health sector has been experiencing severe pressure (Højgaard, 2017), and, since the rise of digital technology at the start of 2000, eHealth solutions have been scrutinized for their potential to connect actors across different public health care sectors to make treatments more efficient. Anticipating an even more mobile future, sundhed.dk has set the strategic goal of developing solutions that capture patient-generated data through, for example, self-tracking devices, in order to make it available to health professionals and the health care system (Sundhed.dk's strategy, 2023).

Sundhed.dk is not only about patients checking and accessing their health data but aims, in a broader societal context, for patient empowerment. This means that the data available on sundhed.dk should allow patients to become active partners in the public health care system, taking active responsibility for the decisions being made in their treatment and thereby playing an active role in the public health care system. To do so, in addition to accessing health data, sundhed.dk offers other services such as a patient handbook explaining medical conditions or an overview of different health services. Even though the initial intention was to create one platform that captures all health data in Denmark, in practice, patients need to use different platforms to check their health data depending on where they live and which kind of treatment they are receiving. Alongside the well-known national platform, sundhed.dk, there are several other eHealth services available that allow patients to write emails to their general practitioners or obtain prescriptions and other services.

Digital health and datafication studies

The term digital health encompasses telemedicine, wearable devices, biosensors, electronic health records and mobile devices. The development of digital health is strongly tied to the development of information and communication technologies, from static websites to interactive platforms. While telecommunication technologies initially accelerated communication distribution, Web 2.0 technologies were discussed in regard to their potential for user involvement as they allowed users to become active content producers (Bruns & Schmidt, 2011). In this era, one of the first attempts to define eHealth was made by Eysenbach (2001). He writes:

eHealth is an emerging field of medical informatics, referring to the organization and delivery of health services and information using the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a new way of working, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology. (Eysenbach, 2001, para. 3).

Ten years later, with the widespread use of mobile phones, the term mHealth was developed to capture the shift towards mobile phones. Having devices that were carried around anytime and anywhere once again changed the field of digital health and allowed for new forms of patient data gathering. Manteghinejad and Javanmard (2021) state that contemporary health technologies entail a shift from disease-centered services towards patient-centered services. eHealth studies rooted in the medical-technical fields are primarily examining opportunities and challenges as well as user friendliness (Kreps & Neuhauser, 2010) and their structural effects (Atasoy, Greenwood, & McCullough, 2019). Studies rooted in the humanities and social sciences have, to a large extent, examined human data practices, especially in the context of self-tracking. Pink et al. (2017) suggest the concept of mundane data as an analytical entry point for an “in-depth investigation into the human experiences, routines, improvisations and accomplishments [...] which implicate digital data in the flow of the everyday” (p. 1). They particularly call for studies that investigate the complex ways in which data becomes meaningful for the everyday user in the context of everyday life.

Flensburg and Lomborg (2021) point towards the still existing analytical gap in datafication studies between research aimed at understanding the technological and infrastructural underpinnings of data and research examining how data is used and understood by people and society in general. They propose a research agenda that attends to the social and technical aspects of data as “distinct yet intertwined” (p. 3) and further point towards communication as a bridging concept that may help overcome this division. They argue that meta-processes of datafication rely on communication technologies and people’s communication about the information they receive. Even though patients generally welcome the possibility of accessing their data (Barello et al., 2019), studies also show that many patients struggle, especially when it comes to making sense of digital health data (Mahnke & Nielsen, 2021). This research takes its starting point in sundhed.dk as a form of communication platform and connects this to early definitions of eHealth as an information and communication technology with the idea of approaching the analysis of all-encompassing datafication processes through a communicative lens. The datafication of health is unique in the sense that digital health data is being produced and provided in a medical context but received in a domestic context, where the individual patient needs to make sense of the data in the context of their everyday life. This study thus contributes to a more nuanced understanding of the profound changes digital health data on eHealth platforms is instigating in people’s everyday lives. We are especially

interested in the communicative situations that arise when patients access their health data as well as how they navigate and make sense of these data experiences.

Data sense-making and communicative gaps

In Denmark, by law, medical tests results and digital health data in general need to be made accessible right away, leading to user notifications at any time of the day. Patients trying to make sense of the data they receive are hence not aligned with doctors' and hospitals' schedules. Digital health data is typically checked for very specific reasons, e.g., to receive test results or doctor's notes, which also makes it a goal-oriented practice.

To examine patients' sense-making practices, we draw on Lupton's theoretical conceptualization of data sense-making, which describes individuals' engagement with digital health data as an embodied practice (Lupton, 2017, 2018). According to Lupton, people are "called on to know their bodies better and more intensely, and to work to interpret these novel forms of information about themselves" (2018, p. 2). From this understanding, data sense-making processes are based on the co-constitutive relationship between humans, digital technologies and data. Drawing on this, we understand the individual's interpretation of digital health data as involving a set of digital skills, and knowledge of the individual's health history and current health situation as well as the specific technological and digital affordances of the eHealth platform. As we set out to investigate how users make sense of their digital health data on the sundhed.dk platform, we focus first and foremost on the communicative situation, when users read and interpret their data. We understand communication as an everyday, cultural- and language-based practice (Carey, 1989; Leeds-Hurwitz, 2009) where meaning is produced and distributed among human and non-human actors in a continuous stream (Barad, 2007).

As described in the background to this article, sundhed.dk started as a more traditional communication and information platform. The IT solution was developed to serve as a digital platform where citizens' health data is uploaded and made accessible to them. It is not possible for users to respond, comment or otherwise contact sundhed.dk or related professionals, only to access the uploaded data. Even though the technology and user interface has developed over time, as has the strategic and political focus, from a communications perspective users are put into a one-way communication situation when trying to make sense of their data, especially because receiving results is not aligned with doctors' schedules. Therefore, we find it useful to turn to Peter's classic text "The Gaps of Which Communication is Made" (1994), in which Peters argues that all types of communication involve gaps that the receiver of the communication has to fill. All communication processes, independent of whether they are face-to-face or face-to-medium communication, are thus without a determined destination. The process of understanding and grasping digital health data is therefore more than a simple process of transmitting information. Peters argues that it is the communicative gaps that receivers (users)

need to fill and make sense of in order to engage in the communicative situation. In the light of this research, we suggest expanding Lupton's notion of data sense-making with Peter's idea of filling communicative gaps. In other words, sense-making of digital health data not only calls for an enhanced self-understanding of the body but also for new communication practices. As communicative gaps are integral to digital health data, patients need to find ways of navigating these new communication situations. Data sense-making can hence be understood as an embodied communicative practice. By adding a communicative dimension to data sense-making, we want to draw attention to the specific communicative situation the users find themselves in when trying to make sense of their health data. In this regard, the more information (data) users can find on sundhed.dk, the more communicative gaps need to be filled. We wish to understand and nuance how users fill those gaps in different ways in their data sense-making processes, and how this may create a multitude of other communication situations.

Digital health data as assemblages

The concept of assemblage (Deleuze & Guattari, 1987; Buchanan, 2020) offers an approach with which to grasp the interrelatedness of myriads of heterogeneous elements that phenomena comprise. It is applied in digital health studies by, e.g., Johnson's (2019) use of assemblage, which understands digital health data as a complex nexus of user-data relationships. Digital health data in this relationship is subject to social, cultural and political influences and can hence only be understood in the respective context. As mentioned above, digital data confronts its users with the need to know themselves better and, as the medical system operates with technical language, it also presents communicative gaps, in other words, language that is incomprehensible and challenging for patients to understand and make sense of. We employ the concept of assemblage to account for the complexity and multiple layers in making digital health data, pointing towards the layers and numbers of relationships that lie in such data. Assemblage in relation to sundhed.dk can hence be understood as a collage of mixed realities, both virtual and physical, such as bodies, test results, diagnostic categories etc. (Johnson, 2019). We further follow Lupton's conceptualization of digital data assemblages as "lively" as they bring together humans, devices, software, data, space, and time and, furthermore, that the interaction with data has implications for human bodies, lives and experiences (Lupton, 2018). Digital health data as assemblage is a network of actors, both human and non-human, where human actors "respond to digital health technologies by shaping them to fit their domestic or work practices where they can" (Lupton, 2014, p. 1352). Digital health data are hence appropriated and domesticated by their users (Carter et al., 2013); nevertheless, they equally shape user practices and experiences.

Empirical material and data analysis

The empirical analysis draws on 24 semi-structured and purposefully sampled interviews with users of the digital health platform sundhed.dk who varied in life stage, education, user behavior, medical knowledge, health history and gender. The three most important factors for us were a variation in user behavior (from heavy users to users that rarely use the platform), medical knowledge (relationship to the medical field) and health history (from no medical conditions to chronic illness). Education, age and gender were the second priority. As we were interested in patients' everyday experiences of the platform, we aimed for a sample that represented a variety of experiences. The interviews were carried out in spring 2022 on an ongoing basis following the principle of data saturation. In the end, our sample consisted of twenty women and four men; fifteen were either currently in education or had just started work. Six were middle-aged and well-established on the labor market; however, one was also in early retirement and three were retired. The age range of our respondents was between 20 and 90. All respondents were Danes and the interviews were hence carried out in Danish; we have, however, translated the citations used in the analysis into English.

All interviews were anonymized, transcribed, and have been inductively coded in several iterative steps (Kuckartz, 2012). This means we scrutinized the interview data for specific emotionally challenging experiences as well as thematic overlaps. As part of the interview coding process, we focused on recording important words, notions, and citations that were characteristic of the given interview. We scrutinized the interviews for words that stood out as central elements, for example: *curious*, *possibility*, *ambivalence*, *incomprehensible*, *medical Latin*, *worried*, *(outside) normal range*. In a shared process, we then went through the lists of words and made clusters with Post-It notes on a whiteboard, e.g., regarding emotions or communication practices, while simultaneously discussing overlaps and contradictions. After looking for patterns and connections, it became clear to all of us that the experience of ambivalence was prevalent throughout the entire material. We then started to cluster the different elements according to the individual experiences of ambivalence and termed them accordingly.

Assembling patient responses

In order to systematically approach our interview data, we first worked methodologically with the concept of assemblage as a way of structuring the thematic analysis. As described in the section above, we worked together in an iterative process to assemble patients' experiences based on an analysis of the empirical material. The assemblage approach helped us work with the interviews in a way that focused on heterogeneous elements – elements that do not necessarily belong to the same ontological category. In this sense, we were not aiming to create assemblages as such, but wanted to be sensitive

towards the human/data dualism. This preliminary analysis resulted in the following word string:

Journals – Diseases – True/false – Laboratory answers – Diagnosis – Medical language
– Medical Latin – Follow-up talks – Doubt – Confused – Stress over bad news – Very
frustrated – Sad – Afraid – Control – Autonomy – Security – Reassurance – Very happy
– Positive – Curious – Tense – Asking family and friends – Google search – Conversations
– Existential questions – Recognition – Alienation

The word string needs to be read as an abstract compilation of the thematic analysis, which we unfold further in the following section. By first creating the word string, we wanted to embrace the description of lived experiences of digital health data and show the complexity that the empirical data entails. While working with the word string as a first step towards assembling patients' experiences, it became clear that the term *ambivalence* best describes patients' experiences of digital health data. According to our material, patients experience digital health data first and foremost as ambivalent – in relation to the received data, the experienced emotions, the needed communication and the negotiation of identities.

Data ambivalence

What we have termed *data ambivalence* is tied to how users of sundhed.dk experience and make sense of the digital health data that is accessible and available to them in general terms. Most of the interview participants perceived digital health data, such as test results, as straightforward data. In other words, data that can give clear answers to the question: "Am I healthy?" However, in practice, digital health data cannot give this expected answer, and then patients begin to learn that there are many meanings and possible explanations. Health data that is not black-and-white may be clear for medical professionals; however, for users of sundhed.dk, this ambivalence makes up a large part of their experience. Martha, who is 55 years old and employed in a public municipality, says in this regard:

Yes, then you can see if your values are within the normal range, but even so you might still need to talk to your doctor or the hospital about what it means. Maybe your values are in-between, so maybe your own reading is not enough, if you're between healthy or sick. Then you need clarification to know how to live your life in the future, for example. You should be careful with self-diagnosing. Then you quickly get scared or worried. "Oh no, your values are not normal. I'm not normal".

Martha is very concerned about her digital health data. As test results are often presented in relation to a so-called normal range, many users start to interpret their results – and hence also their health status – in relation to this so-called normal range. Lisa, who

is a 24-year-old student from Jutland, also had this experience. She has used sundhed.dk primarily in relation to Covid-19 test results and on a few other occasions. The medical language confuses her, and she would like some kind of translation that helps her to make sense of the data and understand the meaning in relation to her personal health situation. She does not have any severe medical issues; however, it is important for her to know precisely what test results mean. Lisa describes to us how she could not understand her digital health data:

Well, I had a few test results I couldn't read myself. [...] I tried to google some of the numbers, but it was a bit difficult because they were also in a graph. [...] I couldn't figure out what was normal for my target group.

Our informant Randi, a 70-year-old retiree, describes her state of mind after accessing her health data: "Because maybe you think you're sick, and then you're not sick after all". She believes the responsibility for understanding the data lies on the patient's as well as the doctor's side. However, even though patients may be scheduled for a consultation with their doctor, many have access to the data long before the scheduled consultation. Pixie, a 22-year-old student, thinks that the available digital health data has become "too much". She uses sundhed.dk a lot and is very reflective about the data she receives. However, she would like much more dialogue with the doctors. She explains:

There is a red exclamation mark next to the variables that are not right, or the numbers that deviate from what they ought to be. And two of them stuck out. And right then, I didn't have the opportunity to talk to my doctor. I think I had the results on Wednesday, and I had to see my doctor on Friday. And I couldn't talk to her in the meantime about what those variables meant. But when I looked it up online, and talked to my stepdad, who is a health care provider, they were some pretty important things. I think it was something about the red blood cells, that I didn't have enough red blood cells.

Unless the patient makes a conscious decision to not look at the test results, it is typically the patient who receives the data first and then must make sense of it. This is due to the technological nature of the platform and Danish law, whereby all results must be made available immediately. There are different ways of dealing with this issue: Some patients call their doctor immediately and ask for an explanation, others start to google and employ their network. Some patients also say they have experienced the data being wrong and doctors making mistakes. For them, it is important to check up on the accuracy of the data, and they find it reassuring that they can access the data to check whether things are in order or not. Maja, a 25-year-old student, describes an incident where she found out by mistake that her intrauterine device was no longer correctly placed:

It was a mistake they once made, where I could see an X-ray they had taken of me. And you really shouldn't be able to see that. And I could also see on the X-ray that the IUD I have, it was very far out to one side, and that really scared me. And so there was nothing wrong with it, but I, so I just expected it to be in the middle, but there it was just like that... and I had no idea about that, but I wasn't supposed to be able to see either of those pictures, I was then told.

Since users are not necessarily experts interpreting in health data, they make sense of and approach the data through a healthy/not-healthy lens. Ideally, patients want to obtain final answers that allow them to act accordingly. While this is one of the goals set by sundhed.dk, it is important for patients to understand the different layers that make up digital health data. These layers lead to new data-human dialogue(s) resulting in multiple minor data sense-making situations. While it was common for patients to share the wish to "know" ("Am I ill?"), digital health data will often not be able to give a definite answer to this question. Relating this back to Lupton's (2018) idea of data sense-making, what data *does* is call upon the patients to get to know themselves better. In this sense, data raises more questions than it gives answers, and this is what *data ambivalence* is about.

Emotional ambivalence

Ambivalence was also central in terms of patients' emotional experiences of accessing health data. Overall, most participants in the study were positive about the ability to access their data, which they found convenient, smart, and reassuring. A feeling of control, transparency, and being able to keep up with their own data was also considered positive. However, patients also report contradictory emotions, for example, that they find it positive to have access but that this very access also causes them stressful and uncomfortable moments. Sarah, 22 years old, explains this ambivalence as follows:

You walk around and stress about bad news. [...] We thought he [Sarah's father] had some sort of cancer, and that made me very sad, and we contacted the doctor who corrected us. So, we had made the wrong interpretation. [...] I feel very informed and I'm very happy when I see a notification [from sundhed.dk]. I often check my blood test results before my doctor, and then I feel I'm one step ahead of my doctor.

Sarah is a diligent user of sundhed.dk but describes her experience of the platform as emotionally distressing, particularly because her mother is sick, and she has been in various situations where the data made her feel uncomfortable. The quote above is about misinterpreted test results. The misinterpretation became obvious after the doctor's consultation. This shows that emotional experiences are strongly linked to *data ambivalence* in the sense that data carries several meanings and that all these meanings provoke a variety of feelings at the same time. As stated above, digital health data does not point

towards one specific answer but opens up a lot of new questions, and hence emotions. We found this *emotional ambivalence* throughout our entire interview material.

Next to the (in)security that test results produce, many users talked about feeling in control and a sense of responsibility for keeping up with their data. Nina, 23 years old, describes how, on the one hand, she feels in safe hands with her doctor's words but, on the other, likes to keep an eye on her data:

I think my doctor's word is an extra security measure that the test results are as they should be. [...] Yes, I think I [feel involved], it's good, it gives a sense of security to keep up with it yourself, so that you can keep an eye out. It is about me, after all.

Nina is studying to become a midwife and has significant insight into the medical system; however, she has also had some negative experiences, especially regarding how she feels she is represented in the data. She has on several occasions been diagnosed with a sexually transmitted infection. This made her feel uneasy, as she worries she will be judged by medical professionals when they see her health records. Whether true or not, the responsibility of keeping up with the data, especially for those users who experience severe or chronic health issues – either for themselves or their loved ones – is tremendous and puts a rather heavy burden on the patient/user.

Maja, who had the incident with the intrauterine device, has been diagnosed with depression. When looking at her health data, she describes her emotions around it:

I think it's uncomfortable to read because it's from a time when I didn't feel super cool. And I can read about the feelings I have talked to them about. Something that I'm actually glad that I'm getting over, but it's just ... you could have written that in your own diary in one way or another. It's just a bit more medical language here.

Overall, the users in this study had emotionally ambivalent experiences when accessing their health data. As our assemblage illustrates above, a broad spectrum of emotions is present in the material: from doubt and confusion to stress over bad news to being very happy, positive, and curious. A key point here is that the broad spectrum is not only broad because it represents many different patient experiences but because individual users experience many emotions in their interaction with sundhed.dk. The *emotional ambivalence* provoked by *data ambivalence* is closely tied to what we have termed *communicative ambivalence*. By this, we mean the ambivalence experienced by users that they are, in a sense, participating in a greater communication flow with health authorities and, at the same time, that sundhed.dk is creating new needs for understanding and dialogue.

Communicative ambivalence

Language used in medical records was central in all the conducted interviews. The results and medical notes that users can access on sundhed.dk are written in a professional medical language that the average user cannot understand. Mark, 31 years old and employed in the private sector, uses sundhed.dk frequently. He has a chronic illness and therefore needs to check his blood test results on a regular basis. On one occasion, he felt that the written and spoken information he received regarding his test results was incongruous and this made him suspicious of the information he had received. It has therefore become very important for him to check the data for accuracy and, more importantly, to talk about his data with others. He elaborates: "I'd say the medical record is written in a professional language that is hard for me to understand [...] I don't feel involved, I almost feel it is only for the health professionals". Even though it is clear that he, as the patient, will check the results, the data is not communicated in this way. The data is pure medical data, typically intended for other health professionals and not the patients who receive it. Leslie, 84 years old and a retiree, describes herself as an observer overseeing the communication flow between two medical professionals: "It is necessary for doctors etc. to look it up and see what medicines this woman is taking, what her diagnosis is [...]". According to Leslie, digital health data on sundhed.dk is primarily a tool for health professionals, and she thinks of it as a great advantage. However, this also emphasizes the experience that many users have: Even though their digital health data is technically accessible, the way it is communicated is ambiguous. Mikkel, who is 76 years old and a retiree, is fascinated by the technical possibilities, and he is further a very active user on sundhed.dk. He says:

It's damn smart because you can continue clicking. It's ingenious. You continue clicking and then you can see and then you can click again. It is an excellent explanation. [...] I don't understand everything because it is in Latin and all that. That's the problem, yes. Still, you understand quite a lot. You do. [...] And sometimes I google it afterwards.

Mikkel is generally content with having access to digital health data, although he finds the Latin medical language difficult, and sometimes googles to make sense of it. Patients often describe how they ask close relatives or friends with medical expertise or knowledge for help in interpreting the data. They may also contact their doctor but, as the doctor might not be available right away, they feel an urgency to either ask friends or google. Googling as a specific form of sense-making shows that patients seek dialogue in their quest to understand and interpret the data. This creates a lot of new communicative needs, as Sarah, 22, who we introduced above, describes:

Every time I have a blood test, I go in to check the result before I talk to the doctor, so I can know what the result was, and I can try and be mentally prepared for what the doctor has to say. My doctor always gives me the results of my blood tests, but I always check them myself just to be safe, and if there are any words I don't understand, I google them.

Even though patients may have negative experiences of googling medical results, it is also a strategy to fill communicative gaps. As Anne, 20 years old and a student, puts it:

If you use it right, then you can qualify your talk with the doctor [...]. But if you're ill and afraid that it is something serious, then it can be a little overwhelming. Maybe get the answers with someone near to you for example.

This quote points to a general observation in the material that the users' interaction with sundhed.dk is not solely an individual user-technology experience in which users silently make sense of the data at sundhed.dk. Rather, the interaction with one's digital health data prompts users to engage with others in interpreting the data as well as seeking out other means of gathering information to understand their health data. Inevitably tied to the language is a feeling of being involved in their health data. Sarah, the 22-year-old student, puts it like this:

Because I don't have a health professional education, I feel involved on an insufficient basis. I don't understand what it means. I do understand what Vitamin D deficiency means, but there are an incredible number of things, when the doctor says, "I'll just run some blood tests on you, just show up on Tuesday and have a blood test", and then suddenly in sundhed.dk you get 15 results from all kinds of tests.

Through this quote, it becomes clear that the ordinary user's ability to understand their health data is insufficient to enable them to become an active participant in the handling of their health data. Other users also mention the health professionals' role in achieving user involvement, for example: "Seen from the system's point of view, I feel included but, from the health professionals' side, I don't feel involved. They [the health professionals] don't invite you to use it"; and "I feel enlightened and involved, I think it depends a lot on the health professionals that you meet". Luna, who is 49 years old and an early retiree, describes the language as "gibberish". She used to work as a social worker but has been diagnosed with chronic stress. She reads a lot of her and her daughter's data, who is diagnosed with cancer. She does not feel that the expertise she has been gathering through the data is welcomed by health professionals.

It is evident that having medical professional knowledge or having access to it in one way or another is important in order to be an active and involved digitalized patient. To sum up, users who do not have any professional medical knowledge need to build up medical interpretational skills to make sense of the data. They do so either through googling, asking relatives or friends, or asking their doctor. As Luna points out, taking on the role of involved participatory patient also requires the health professionals to let patients be involved in the data:

If the patient or close relatives are not important partners of the health professionals, then I don't know, really. But it demands that you're prepared for it. And you can meet doctors

who think it is a huge advantage, and you can meet some who think that you're an annoying "Inquisitive Tom", who just needs to listen.

Identity ambivalence

Finally, yet importantly, the material draws attention to issues relating to questions of identity and experience of a (healthy) self, as well as raising existential questions. When users access their digital health data, some find ways to use it as an extension of their general experience of their health, for example: "So it functions like a log for me." (Sarah, 22 years old). Pixie, however, does not experience the accessed data as a positive addition to their experience of their healthy self:

It is very impersonal. [...] I had to go through all kinds of things at the hospital and sit alone and have tests, and more blood tests. And then I just ended up getting a message in three lines that nothing was wrong. I felt it was a bit alienating in a way.

The ambivalence between recognizing oneself in the accessed data or feeling alienated by the experience of the data is something that also comes across when users are asked if they find their digital health data representation true to their experience of themselves. Nina, the 23-year-old student studying to becoming a midwife, answered as follows when asked how she saw herself represented in her data:

That I'm a young girl having lots of sex [laughing]. Because most of the things I can access are everything from chlamydia test results, herpes test results, insertion of IUD [intrauterine device] as well as removal, all these kinds of health check-ups. It is a bit like "well okay" [...] I wouldn't say it's misleading but it's not the whole truth or the whole picture one gets from looking through my medical records.

This emphasizes that digital health data are not neutral information to users but are always interpreted in relation to the discursive context (e.g., lots of STI test results and lack of other content) as well as the lived reality of the user. Luna, the early retiree, describes how she checks up on the data recorded about her: "It is more the recording, you know the written, the symptoms, is it correct? That they have understood what it is about. That what I told them about my symptoms is what they have written down".

Some users actively engage with their digital health data in relation to their health practices, for example, Mark, the 31-year-old private sector employee: "I also keep an eye on the different numbers and values that come from the blood tests, and for me it works as a motivation that I can see a positive change in, for example, my blood sugar or other things. Or that I'm well and healthy and I can see I made a difference." The digital health data thus becomes integrated into the user's life and becomes an indicator not just of well-being (e.g., good test results), but of the user's ability to change and improve their life.

For others, digital health data raises existential questions. Nina, who is 55 and employed as an academic at a Danish university, accesses her digital health data as a way

to look at “your own mortality”. She uses sundhed.dk a lot but has a hard time finding the information she needs on the platform. She is also someone that googles a lot and feels that she takes on a lot of responsibility regarding her health:

[...] it is clear that there is something inherently negative in having to look up and find out something about illness. Yes, there is an unpleasant experience in having to look up and search for it. It is not necessarily a very nice process, looking for what my last lab test says? So it's not a nice feeling, but it's not the website's fault. No, it's because it's a really uncomfortable thing to deal with your own mortality.

The experiences of these patients show that accessing digital health data is not only a matter of receiving an answer, but the data also confronts patients with their idea of being healthy.

Discussion

The in-depth description of users' experiences of sundhed.dk shows that citizens do get involved in and connected to the public health care system when they access their health data online. However, the analysis also shows that when digital health data is accessed, communicative gaps occur and the need for more information and communication arises. While accessing the platform to seek answers, more often the opposite happens. The data provided raises several questions and therewith insecurities. This points towards the issue of how patient empowerment can be achieved via communication platforms such as sundhed.dk, and whether it can be achieved through such platforms alone. Users generally tend to seek the data that is accessible to them but, as the empirical analysis has shown, accessing one's health data in a meaningful and empowering way requires specific interpretational skills and/or a network. How, then, can the public health care system make sure that users are able to fill the communicative gaps? Here, the analysis points to specific barriers such as specialist (difficult) language as well as numerical test answers that offer too broad a span for interpretation – in other words, too many gaps to fill. Another issue is the experience users have of health professionals not always being willing or able to support the patient's engagement with and understanding of the data provided in all its facets.

Literature on patients' engagement with and interpretation of health data points to the interplay between the presentation of data and people's sense of self (Hacking 2007, Rose & Abi-Rached, 2013). As mentioned above, Lupton (2020) explains how we have become data selves as we interpret ourselves through digital health data. In a similar vein, Dumit (2010) writes about our objective selves and what he calls objective self-fashioning as a way of describing how we incorporate scientific, medical, and technical information into our lives and knowledge about the self. As the study also demonstrates, digital health data, just like all kinds of health data presented to us, affects how we think of ourselves

and our opportunities for action. What is especially interesting regarding digital health data accessible from the home, however, is the extra layer of ambiguity and uncertainty it produces. We receive data at home, without professionals to consult, and therefore we often turn either to google or friends and relatives to interpret the data. This identified experience of ambiguity and uncertainty emphasizes the importance of meaningful communication practices – whether online or in the consultation between doctor and patient. The emergence of this new medical-domestic space (Mahnke & Nielsen, 2021) requires new forms of dialogue between doctor and patient, potentially involving correction of misunderstandings and misinterpretations of the data on the patient's side. The level of ambiguity or insecurity, however, naturally depends on the complexity of data and the extent to which it affects the patient's health. Having difficulty understanding a blood test may be different for a young and healthy person waiting for the result of a general health check-up than for a cancer patient waiting for and not understanding a blood test result. The effort required to minimize the communicative gap therefore also differs according to the severity of the type of data and what it represents.

The patient's ability to recognize themselves in the data presented to them is something worth considering as well. As we see in the analysis, data on sundhed.dk does not always correspond to or represent how the patients see themselves. The impersonal data that often refers to a very specific part of the patient's life only depicts a limited version of the person. Here again, however, the consequence of this potential identity ambivalence differs according to the situation. While the young student, who sees her chlamydia test results as presenting only a very limited picture of who she is and what her health status is, may joke about the data representation of her, the psychiatric patient who cannot recognize him- or herself in the health professionals' notes may be worried about the consequences of how he or she is portrayed (Strudwick et al., 2020). It is hence of great importance to pay attention to user experiences of dissatisfaction and confusion, as accounted for in this material, and to consider how to fill the arising communicative gaps.

Conclusion

eHealth platforms are created with the best intentions of empowering patients through data access; however, in everyday use, patients are often on their own when it comes to understanding complex medical communications. This shows that eHealth platforms such as sundhed.dk are much more than digital information and communication platforms. They play a role as communicative actors in the public health care system, shaping not only the patient-doctor relationship but also creating new patient-data communication. Even though many patients may start accessing their health data with the idea of checking whether they are healthy or not, throughout the course of the process they become deeply affected by it.

This study has examined patients' personal experiences when accessing their digital health data. It has shown that patients are generally positive about the possibility of accessing their health data. However, the possibility of patients seeing their health data also creates deeply ambivalent experiences, with regard to the data itself, the emotions provoked, the language used and the existential questions raised. Being able to access data prior to a scheduled doctor's appointment creates data ambivalence, which prompts a situation where patients must employ specific sense-making strategies to understand and interpret the data: Many google, others ask their network. However, that patients are pushed into the role of being the first interpreter of health data is deeply questionable. The fact that health data is mostly presented in Latin or medical abbreviations creates communicative ambivalence, which results in communicative and interpretational gaps that need to be filled. This, in turn, creates emotional ambivalence which, for example, involves ambivalent feelings, such as being prepared and feeling safe as well as being confused and worried. This is especially the case because digital health data cannot provide the definite answer that most patients are longing for. Finally, patients may encounter identity ambivalence, which occurs in relation to accessing representations of themselves in their health data, especially when integrating their datafied medical self into health-inducing routines or encountering themselves as potentially sick. In conclusion, it can be stated that patients' access to their digital health data creates ambivalent experiences, often challenging previous conceptions and self-understandings. Patients' access to digital health data may foster experiences of empowerment and recognition; however, it most likely also leaves the patient insecure, puzzled and with new unanswered questions. We therefore suggest that further studies look deeper into the communicative situations that arise and start examining the different forms of communication that patients employ to make sense of digital health data.

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