CHAPTER 8

Disconnective care

Chronic illness and digital patienthood

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ABSTRACT

As the development of new digital welfare solutions to an increasing extent is carried out in public–private innovative partnerships, the provision of care and the practice of patienthood are changing. In this chapter, I draw on a pilot study consisting of an expert interview with an employee at a global tech-pharma company and two patients with IBD (inflammatory bowel disease) to tease out ambivalences and ways that disengagement and disconnection emerge as "disconnective care" in digital patienthood. Two narrative vignettes are presented and illustrate 1) digital patienthood as reinforcing the need for "boundary work" within a moral economy of (health) data-sharing, and 2) how partial disconnection is negotiated when full disconnection is not an option because of the everyday management of illness being dependent on digital media technologies. I point to the need for an ethics of "response-ability" in relation to chronically ill patients navigating digital patienthood as part of everyday life.

KEYWORDS: digital patienthood, disconnective care, boundary work, moral economy, response-ability

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Introduction

> They [the public sector] don't have the resources that we have in these matters and because of this, it has been a collaboration, also with patient organisations to make sure that they [the patients] are empowered to take responsibility themselves. And as you well know, the more information you have, the better off you are.

The above quote comes from an expert interview I conducted in May 2021 with an employee at a Danish subsidiary of an international company supplying pharmaceutical products and digital health technologies to the home market. The employee was describing the collaboration with the Danish public health sector concerning the development and implementation of Lev med IBD [Live with IBD], a health-tracking app launched in 2020 and directed at patients living with the chronic illness inflammatory bowel disease (IBD). In this chapter, I present two narrative vignettes made from qualitative interviews with two patients who have IBD. These vignettes draw the contours of an everyday life with digital technologies and chronic illness that do not fit easily with the notion of "the more information you have, the better off you are". Rather, the vignettes respond to this statement in ways that show its inherent "techno solutionist" (Morozov, 2013) approach to the provision of healthcare. Techno solutionism, as Morozov framed it, combines a reductionist approach to complex and fluid social problems with whatever is envisioned to be the latest in technology – artificial intelligence, Big Data, machine learning, and so on. Over the last two decades, digital technologies have been assigned a key role in the public provision of healthcare when working towards enhancing time efficiency and lowering costs without compromising the quality of care provided (PLO, 2010; Swan, 2012; Topol, 2012, 2015). The techno-solutionism in the interview quote opening this chapter illustrates an approach to healthcare in which the problem in need of fixing is defined not as much a *health*-related matter as it is a *data*-related matter: The problem that patients want to avoid is being underinformed, the risk of lacking information, or data, and the health-related consequences this is suggested to potentially introduce. The solution, then, is for patients to produce, circulate, and engage with information, with data – "the more, the better". As pointed out in the quote, this at the same time requires and produces *empowered* and *responsible* patients. These patients act in ways that enhance the amount of data generated and information obtained. Data is thus placed in the driver's seat when a digital technology like the app in question is developed and envisioned to assist patients and healthcare providers alike in managing a chronical illness like IBD.

With this chapter, I wish to present a small-scale intervention against this techno-solutionist assumption and the promises it assigns to digitally engaged patienthood. Through a pilot study consisting of qualitative interviews with

two patients who have IBD, I tease out some of the tensions and ambivalences arising as patients living with chronic illness in a highly digitalised public healthcare sector are being digitally disengaged or temporarily and partly disconnected. I speak of this as "disconnective care" practices carried out by patients within digital care infrastructures (Langstrup, 2013; Lomborg et al., 2020). By doing so, I follow Lomborg and Ytre-Arne's (2021) call to consider disconnection research not as a distinct subfield but rather deploy it as a lens to examine core issues relating to media and communication. I hope to invite further empirical explorations of *how*, *why*, and *when* disconnection and chronical illness interweave (or clash) in the everyday lives of patients in the Danish healthcare sector. I continue the chapter by introducing the theoretical framework tying together the concept of informational medicine with transformations of contemporary patienthood and notions of care, more specifically caring for others through data "sharing", as well as caring for self through disconnection. A brief methodology section leads to the analysis consisting of the two vignettes. I then discuss contemporary patienthood and the need for response-ability within digital care infrastructures. The chapter ends with concluding remarks summing up the arguments raised and calling for further empirical work bridging the fields of disconnection and critical digital health.

The turn to informational medicine and "digitally engaged patients"

Whether framed as digital health, eHealth, mHealth, or Medicine 2.0, the interweaving of healthcare with digital technologies has created new ways for patients to manage, keep track of, become informed about, and communicate with healthcare professionals. Under these labels, digital technologies are envisioned as key actors, as the public health sector and private actors alike work towards delivering "time- and cost-efficient healthcare of high quality" (PLO, 2010). The interview quote in the beginning of this chapter speaks of a public–private collaboration where the different actors (the public health sector, patient organisations, and the private technology- and pharma-company) work together in developing digital healthcare products and services that will empower patients, and, through the production of nuanced health information and data (e.g., through use of tracking technologies) create participatory, responsible patients. Telemedicine-like e-consultation (Assing Hvidt et al., 2020; Atherton et al., 2018; Klausen & Grønning, 2021) and video consultation (Lüchau et al., 2021; Thiyagarajan et al., 2020) are implemented to provide easier, cost-efficient access to private health records, consultation booking or cancelling, and medical expertise. In 2009, it became mandatory for general practitioners in Denmark to offer e-consultation to their patients, and more recently, the uptake of video consultation rapidly gained pace during and after the Covid-19 pandemic (Jepsen et al., 2022).

Technologies such as implanted biosensors and a continuously expanding market of health-tracking apps (Kristensen & Ruckenstein, 2018; Lomborg et al., 2020, 2021; Lupton, 2017b) allow patients to monitor their health and illness and on the basis hereof engage in different practices of self-care. If we not only focus on health technologies as defined by the World Health Organization as being "the application of organized knowledge and skills in the form of medicines, medical devices, vaccines, procedures and systems developed to solve a health problem and improve quality of life" (WHO, 2024), but broaden the scope to also include the Internet and social media as digital health technologies, patients can seek information about health, illness, and treatments, as well as post or read stories about illness (McCosker, 2013; Stage, 2017) and share data visualisations (Kennedy & Hill, 2018). Running parallel with and supporting patients in becoming more digitally engaged is the turn towards "informational medicine" within healthcare. Sarah Nettleton (2004) coined this turn and pointed to a move away from "mechanical" to "informational" or "e-scaped medicine". This turn involves a move from relying more on the haptic (touch) to relying on information generated by patients and healthcare providers alike and where "expert patients", instead of doctors, manage their illness (Nettleton, 2004: 666). Informational medicine rests on the assumption that more information leads to both better healthcare and economic efficiencies. This is obtained partly through processes aiming at increasing patient participation and empowerment, as illustrated in the opening quote, and partly through providing healthcare services with data envisioned to improve service delivery and medical care (Dentzer, 2013; Swan, 2012; Topol, 2012, 2015). In this framework, the ideal patient responsibly takes part and is invested in self-care. More so than a *recipient* of treatment, the patient is scripted as a *participant* in treatment and placed "at the centre of action-taking in relation to health and healthcare" (Swan, 2012: 97). Viewed as "managers" (Greene & Hibbard, 2012) of health and healthcare, patients are encouraged to assume what Carsten Stage (2017) critically referred to as an "*entrepreneurial* attitude" to health and treatment. Within critical digital health studies, Deborah Lupton (2013) has discussed how "the digitally engaged patient" emerges at the intersection of discourse about patient engagement and informational medicine. Adopting the role of both consumer and citizen (Mol, 2008), the digitally engaged patient is envisioned as rationally assessing options and making choices (of general practitioner, medical products, procedures, and treatments), to become an active participant in treatment (Lupton, 2013: 258). As a part of the digital managing of health and illness, and communication with healthcare professionals, responsibility is to a growing extent bestowed on the patient.

Pushing back against the imaginary of the digitally engaged and empowered patient is everyday life with digital patienthood. In the everyday, technologies might not always be integrated as seamlessly in treatment as

promised. Experiences of empowerment might be countered with experiences of frustration when technologies function improperly or completely fail. Participation might be hampered by aching bodies requiring rest, and the need for rest may take many shapes: rest as in sleep and recovery, rest from being part of the public healthcare system, rest from the role and stigma of "patient" and "chronically ill", and rest from the digital technologies which form part of the care infrastructure. Therefore, we need to empirically explore the perspectives of both patients and healthcare professionals in relation to dilemmas arising as the patient role becomes increasingly interlaced with digital technologies, responsibility, and active participation. The empowered, informed, and entrepreneurial patient role will of course be beneficial for some patients and in some treatments. For other patients, digitally engaged patienthood can compromise the opportunity to live a "good life" with chronic illness or to live an "authentic" life, which in our time, as Syvertsen and Enli have argued (2020), has come to include occasionally reflecting on and disconnecting from one's media habits and repertoires. This points to a dilemma which is particularly pressing for patients living with one or multiple chronic illnesses. For these groups, the use of digital technologies as part of continuous treatment is crucial in the everyday management of life with a chronic illness – or even sometimes to stay alive, for example, implants such as glucose monitors or pacemakers. Patients with chronic illnesses thus do not have the same opportunity – or privilege – to opt out of using digital technology and disconnect or "detox". The question of digital disconnection in relation to patienthood and the provision of care in the Danish healthcare sector is then charged with tensions – firstly because patients must be digitally connected in order to receive care, and secondly because of the vulnerability of the (chronically) ill body in need of care. There is a need to advance critical understandings of how disconnection – as well as the lack of opportunity to fully or even partially disconnect – is shaping contemporary patienthood: Which new responsibilities arise when patients desire and practice disconnection? And what might the reasons for disconnection be: Detoxing and self care? Avoidance of media or further digital labour? Activism? Through empirically informed understandings of how chronic illness and digital disconnection coincide or clash in contemporary patienthood, we can productively nuance techno-solutionist approaches to digital patienthood. What is at stake when digital disconnection can cause a patient to miss a hospital appointment sent to their eBoks,[1] to forget taking the correct medicine on the correct days because the notifications and alarms are set up on the smartphone, or to otherwise neglect elements in a treatment plan? And what does it feel like for patients to disconnect? Disconnection studies urge us to approach digital disconnection as norm and culture (instead of an individual practice and problem) (Moe & Madsen, 2021) within people's everyday digital media habits and repertoires. I combine the above when

examining digital disconnection in contemporary patienthood. This pilot study outlines an agenda for critical digital health approaches (Lupton, 2014, 2017a) within disconnection studies (Fast, 2021; Syvertsen, 2020; Syvertsen, et al., 2019). Critical digital health approaches critique techno-solutionism in healthcare through sociological, anthropological, science and technology studies, and media and cultural studies frameworks and address the broader implications for how knowledge of the body, health, and illness is developed, and for issues relating to medical and public health practice, power relations and the doctor–patient relationship.

Disconnective care

> Common to all is that those who restrict their digital media use have goals that are important to them, beyond media. Digital detoxing is not just about self-optimisation but about fulfilling social roles and responsibilities and being in tune with ideological convictions or professional affiliations within a broader context. (Syvertsen, 2020: 120)

In her work on disconnection, Trine Syvertsen along with colleagues has drawn attention towards the politics and practices of disconnection (Syvertsen, 2020, 2023; Syvertsen & Enli, 2020; Syvertsen et al., 2019) placed within the broader context of neoliberal self-regulation. As mentioned, the provision of healthcare is becoming further tied up with digital infrastructures and new digital welfare solutions, hereby reinforcing the ideal of the digitally engaged patient. These "care infrastructures" (Lomborg et al., 2020; Prainsack, 2017; Schwennesen, 2019) allow treatment to travel and take place, and as argued by Henriette Langstrup (2013: 1010) in her conceptualisation of chronic care infrastructures, "they tend to be sunken into other structures and social arrangements". Chronic care infrastructures consist of various elements – daily routines, scheduled control visits, medication, doses, and more – which to a growing extent are becoming embedded in the use of digital technologies. Returning to Syvertsen's argument that people do not only disconnect *from* media, they also connect *to* something (roles, responsibilities, or ideological convictions), we then can ask what might disconnection from digital care infrastructures be about? What do patients wish to disconnect from, and what do they orient themselves towards by disconnecting? And how does it affect everyday life with chronic illness when patients wish to fully disconnect, but they cannot do so since disconnection from the care infrastructures is not always an option? Focusing on practices of (partial) disconnection and variants of digitally disenganged patienthood reveals something about struggles, desires, ideals, and routes or impediments to living a "good life" with chronic illness. I use both "disconnection" and "disengagement", as the former entails a deliberate periodic disconnection from social or online

media or strategies to reduce media involvement and "advocates balance and awareness more than permanent disconnection" (Syvertsen & Enli, 2020: 1269). I speak of the digitally *dis*engaged patient to frame those uses of digital technologies which do not revolve around detox, balance, and awareness, but are rather about keeping one's involvement in digital care infrastructure and technologies at a constant low. I suggest that the term digitally disengaged is appropriate to describe the media use illustrated in the first vignette. My approach to disengagement is inspired by Heather O'Brien and Elaine Toms's (2008: 944) definition: Disengagement occurs when a participant has made an "internal decision to stop the activity or when factors in the participants' external environment caused them to cease being engaged". To disengage then means to "sign off", either by "ceasing to be engaged, or to stop using the system altogether" (O'Brien & Toms, 2008: 948). In the first vignette, the patient's decision to keep digital media use in relation to illness management disengaged is a deliberate one which revolves around boundary work. In the second vignette, partial disconnection from digital care infrastructures affords moments of tuning into what the patient describes as a more authentic self through "detoxing" (Syvertsen & Enli, 2020). Through both the continuously disengaged and the disconnected mode of digital patienthood emerge practices of care. In both cases, the practice of digital patienthood is analysed through a distributive conceptualisation of care (Mol, 2008; see also Andelsman Alvarez, Chapter 12 in this volume, for perspectives on more-than-human care relations). Care is relationally achieved in chronic care infrastructures consisting of technologies and various human actors. The provision of care, then, emerges not as the task of the healthcare professional alone, but as a relational endeavour accomplished through collaborations between the healthcare professional, the affordances (as well as promises and ideals) of digital technologies, and the chronically ill body. Caring for a chronically ill body within these infrastructures sometimes implies practices of "disconnective care", where patients are continuously disengaged with digital health technologies or (partially) disconnected from the care infrastructure.

Method

The semi-structured interviews (Kvale & Brinkmann, 2009) were conducted in October to December 2021 in Copenhagen as part of a pilot study, and they form part of the larger project "Datafied Living". Out of each patient interview, I developed a "narrative vignette" (Lomborg et al., 2020). Traditionally, vignettes have been used in nursing and healthcare research but have recently been introduced as a method in data studies (Lomborg et al., 2020; Maslen & Lupton, 2019) and critical digital health studies (Klausen, 2022). The narratives mobilised by these two vignettes do not allow any generalisable tendencies within

digital patienthood. Instead, the vignettes serve as a small-scale intervention against the highly celebrated figure of the digitally engaged patient and point to disconnection as a future avenue for research in digital patienthood.

The first vignette sheds light on how digitally disengaged patienthood both affords a practice of self-care while also imposing ambivalences and concerns about potential data going to waste. Being a digitally disengaged patient implies managing ambivalences connected to staying disengaged in a thoroughly digitalised healthcare sector *and* in a time marked by "moral obligations" to share data (Fotopoulou, 2018). We also meet the patient's concerns about how an increase in use of digital technology in relation to illness could impose an unwelcome blurring of boundaries between the (mostly symptom-free) everyday life and illness-related practices. This digitally reinforced blurring of boundaries requires the patient to carry out what I refer to as "digital boundary work", inspired by Blake E. Ashforth and colleagues (2000). The second vignette speaks about the paradox of partial disconnection as care for self, when complete disconnection is not an option because treatment is bound up with a digital care infrastructure. In the second vignette, partial disconnection serves as a way of turning away from media, screens, and information overload and instead attuning to "intuition" and a more authentic and (partly) media-free version of self.

The digitally disengaged patient

Self-care through digital boundary work in a moral economy of data-sharing

Søren is 30 years old and was diagnosed with IBD four years ago. Søren does not use an IBD-tracking app but he occasionally uses MyChart to communicate with clinicians, read and keep track of test results, and make sure that his values "stay within the green area", that is, the recommended values of, for example, vitamin D levels in the blood. After being asked if he uses any sort of tracking device or app in relation to his IBD, he replied that he did not. He also stated that he tries to keep illness-related technology use "at a low", preferring to deal as little with his illness as possible, which is often the case for patients with chronic illness (Danholt & Langstrup, 2012). Søren elaborated on his feelings and thoughts about data and how he imagines tracking data could contribute: "I didn't know that there was this opportunity to track; had I known I think I would have done it, because I do want to… I think it's a waste of data". And in the same vein, a little further into the interview: "It's a bit of a shame with all that data really… Like, I feel like there's data going to waste. I imagine I'm not the only one feeling this way". For Søren, the openness to the idea of health-tracking is connected to the imagined benefits of data-sharing and thus preventing data from "going to waste". This we can approach through José van Dijck's (2014:

198) "dataism", understood as an ideology or secular belief in the "objective" quantification of tracking all kinds of human behaviour, and what knowledge Big Data is capable of generating. Interestingly, it is the common good, particularly medical research, and not himself Søren wished to benefit from his data: "Through this data collection it would be easier for the healthcare sector to organise the medication of each person". And he continued, "it would be with the sole purpose of producing some data that could be used by somebody. It would not be for myself [...] It would be solely for someone who lacks that data". In the dataism at play here, we see how the paradigm of informational medicine and the practice of digital patienthood become tied up with a "moral economy" connected to data-sharing. Aristea Fotopoulou (2018: 144–145) argued that our cultural understandings of data "sharing", including how we understand the self and our social responsibility, are shaped by and are shaping the emerging culture of quantification. This creates a situation where contemporary cultural understandings of self-tracking and data-sharing are underpinned by a "moral economy": "Its values prescribe new ways of connecting with other and enacting 'good citizenship' through data practices and normalize these practices as our means to an altruistic sociality" (Fotopoulou, 2018: 145). For Søren, the idea of sharing data is very clearly connected with both a desire to contribute but also to the ambivalence arising from the fact that he is not, at least not as much as he feels he should be doing. Applying Fotopoulou's notion of the moral economy of data-sharing within the context of digital patienthood thus allows us to approach patients' sharing of health data as potential enactments of "good (digitally engaged) patients". Through the affectively charged moral economy of data-sharing, chronically ill bodies are then being turned into production sites because of the data these bodies are imagined to be producing. In contemporary digital capitalism, where personal information disclosure is being reframed as "sharing" (Fotopoulou, 2018: 150), we see in Søren's eagerness to contribute and in his belief in the usefulness of the data another aspect of how digital patienthood becomes tied up with labour. Søren elaborated on what the imagined pros and cons would be if he were to track using an IBD app, and again he set off by taking the perspective of the recipient of the data and not himself: "There would be some holes every now and then in the data. But of course it would be better than no data at all". The dream of the complete (big) dataset is borne within the ideology of dataism (van Dijck, 2014), and the belief that an incomplete dataset with "holes" would still be better than no data at all again testifies to the imaginary surrounding datafication and what quantified data can do.

A little further into his thoughts about the pros and cons concerning IBD-tracking, Søren touched upon the risk of the illness becoming too present in his everyday life (where he most of the time does not feel symptoms) due to the (imagined) tracking:

> It would be easy if I could just, like every time I have been to the toilet, then I'm there, in the situation, and ok fine… Boom then I can simply track "Toilet visit", "Pain", "Whatever", like the necessary things and then put it away. But do I then also have to remember to track every time I eat and how I feel? Then it becomes more… Then I have to spend time and brainpower on my illness that I would much rather spend on my work or anything else really. And then the illness would take up too much space.

In this thought experiment, Søren imagined an everyday life with IBD-tracking: His disengagement is not replaced by its opposite (a high level of engagement), but instead by a middle position where the technology is tamed in a way that does not blur the boundaries between the patient role and everyday life (Syvertsen et al., 2019). He knows from his life with the illness the frustration connected to having to go to the hospital every four weeks "even though I feel healthy", and this interruption by an IBD-related activity into an otherwise non-IBD affected everyday life disturbs him. Søren imagines the tracking would work similarly, as an unwelcome reminder of his illness. Though being digitally disengaged causes ambivalence because of the feelings attached to the data going to waste, disengagement affords a necessary delineation of everyday life, where he feels healthy most of the time. Illness-related digital tasks remind him of the patient role and gets in way of his ideas about a good life with chronic illness. The use of digital health technology such as tracking can thus create a blurring of boundaries for the patient between feeling ill and healthy. This requires boundary work (Ashforth et al., 2000) to be performed to avoid the patient role from leaking into everyday life.

The disconnected patient

Disconnective self-care and making do

Ole is 34 years old and works as an electrician. He was diagnosed with colitis (inflammation of the colon) in 2018, received ostomy surgery in 2019, and has had a colostomy bag since. Ole describes himself as "his own healer" and is quite sceptical towards the Danish healthcare sector, telling of several bad experiences of being a patient himself and having relatives hospitalised. He feels that the public healthcare sector has failed to provide him with care and treatment that allows him to live a good life with his chronic illness. Because of this, he has sought information and advice online on alternative ways to treat colitis, and in collaboration with a private clinic, he has devised a treatment plan that he follows rigorously, as he experiences beneficial health effects from this. He has spent what he perceives as "a lot of time" in Facebook groups for people with different colon diseases, as he wanted to share information about the beneficial effects of his current alternative treatment:

"I'm not expecting someone to send me a million kroner or to nominate me as anything, I'm just hoping someone can benefit from my experiences". As part of the treatment, Ole has to keep track of daily breathing exercises and medicine intake (three to five times a day) and weekly routines such as meditation and coconut oil enemas. To assist in the daily and weekly management of treatment, Ole uses both the calendar function on his smartphone as well as a smartwatch, which he bought with the sole purpose of keeping track of his treatment and timing his breathing exercises. He receives notifications on the watch several times a day: "The watch is all about medication. When do I take these and those and when do I do this and that etcetera". Ole explained: "It [the watch] rings here and there and from time to time. And it prevents your everyday from becoming so stressed, because you won't forget stuff". He also tracks sleeping patterns on the watch, "but I don't really get anything out of it", he says, and adds, "it tells me that I slept badly, and so what? [laughs]". The watch also tracks pulse and exchanges this data with an app on his phone in which he sometimes looks into levels of oxygen saturation. He opened the app during the interview: "Right now my heart [rate] is 86. I don't know what that is, I don't use it. It's kind of fun – you can see if you've walked 1,000, 10,000, or 18,0000 steps and then go 'yes!'" Besides the watch functioning as an alarm clock three to five times a day and his smartphone's calendar function, Ole says that he has "thousands of Post-it notes at home with small reminders on them". Ole delegates part of the responsibility for keeping track of his treatment to different technologies: The watch, the phone, and the Post-it's on his walls support him daily in remembering when to do what in relation to treatment. Responsibility and care are thus distributed and emerge relationally within infrastructures consisting of (digital) technologies and human actors (Kristensen et al., 2021; Schwennesen, 2019). During the interviews, Ole also talked about the negative effects he experiences that media, especially the news and social media content, have on his mental health: "It's depressing, social media, both what people choose to post and what they choose not to post. I'm pretty anti social media". And with regard to the news: "I would never watch the news. It's brainwash […] News and newspapers serve only the one purpose of creating chaos and fear in people. I'm not up for that". To care for himself, Ole occasionally takes what he refers to as a "retreat" in his summer house, which he described as "therapeutical", involving laying on the beach during summer and swimming during winter as well as different digital disconnection practices:

> My phone is on silent, and I'll answer it when I notice there's been a call. I do not bring my laptop – it's about just being able to be yourself and being able to be yourself without watching TV or listening to music and so on. I believe this is good, and it is.

He also talked about how online health information can overwhelm him and cause him to worry about his illness flaring up: "but I found out, that then you just have to leave it be [the online health information], turn if off and follow your intuition". Digital media technologies, news, and online health information in combination make up an entity which is experienced by Ole as getting in the way of him "being himself", that is, a more authentic version of himself. However, Ole needs especially his smart watch to not forget when to take medication, and because of this, the watch stays on while the smartphone is placed in a drawer during his retreats. When asked about whether wearing the watch affects him during his retreats, he explained:

> Sometimes it does disturb. But I've probably just come to terms with that I need to suppress this. It happens [notifications from the watch] because I need to do these things. It's not: Remember to go for a run today. *It's something important*. It's going ok, but I can be in the garden and then it rings and tells me I need to do this and that. And then you just have to do it [emphasis added].

A chronically ill body situated in a digital infrastructure of distributed responsibility and care can only partially disconnect from this infrastructure. As the technological affordances have become vital components in the human–technology "care teams" (Piras & Miele, 2017) managing the illness daily, the opportunity to fully disconnect or "detox" is hampered. Some chronically ill bodies thus must stay connected, completely (e.g., patients with pacemakers or continuous glucose monitors) or partially (as Ole) to a digital care infrastructure. This then requires that the patient on their own does repair work (see Scott Hansen, Chapter 10 in this volume) and circumscribes ideals about full disconnection. Patients sometimes have no other option than to make do with whichever partially disconnected set-up that allows for the vital parts of the digital care infrastructure to still be functioning. This points to self-regulation (Syvertsen & Enli, 2020) as an integral part of digital patienthood: It is the individual's responsibility to assess the potential risks and gains of repair work within the digital care infrastructure. We thus need to pay closer attention to disconnection and "digital reflexivity" (Fast, 2021) in patienthood to see partial disconnection and forms of disengagement as practices of such reflexivity.

Response-ability

The vignettes shed light on practices of disconnective care as part of digital patienthood and point to how chronic care infrastructures involve different ways of self-regulating for patients. For Søren, disengaged use of digital health technologies afford boundaries between patienthood and symptom-free everyday life, but comes with ambivalent feelings of not contributing through

data-sharing. Ole practices partial disconnection to attune to a more authentic version of himself but is in a position where only partial disconnection is possible, and he thus has to make do. In different ways, the two vignettes draw attention to questions of "response-ability" (Lomborg et al., 2020; Schwennesen, 2019), that is, "who or what is able and willing to respond to the needs of others" (Lomborg et al., 2020: 8). In a public healthcare sector increasingly marked by public–private innovative partnerships, as is the case described in the opening quote of this chapter, the question of who might be responsible for answering to – or caring for – patient needs, for example, for disconnection, becomes a highly pressing one with no simple answers. The digital care infrastructure is made up by various actors, values, interests, and spaces: healthcare professionals, tech-developers, hospitals, clinics, private homes, eBoks, MyChart, smartphones, smartwatches (including heartrate and sleep trackers), data visualisations, and so on. With the development of new digital welfare solutions, as Nete Schwennesen (2019: 179) pointed out,

> the intention was not only to make care work more efficient by making those products available for use by the Danish welfare state, but also to export them to a global market, thereby providing the basis for an economically sustainable welfare state in the future.

In public–private digital welfare solutions, the embedding of patients in the double role of care recipient and "data produser" (Michael & Lupton, 2016) obscures whose interests are being looked after and blurs questions about recipients (app and platform owners, pharma and/or healthcare professionals?) and ownership of data, and thus of who is response-able for providing patients with guidance about what to track and when *not* tracking, or disconnecting, is an option as well as in relation to interpreting the tracked data .

Developing ethically response-able care infrastructures, I argue, also involves considering how the larger cultural framework of digital detoxing and self-regulation (Syvertsen, 2020) might impact practices of digital patienthood and place especially patients living with chronic illness in ambivalent and not easily navigated situations in which they are themselves responsible for assessing which digital health technologies they can disconnect from, for how long, and with what effect. The techno-solutionist approach to healthcare provision present in the statement "the more information you have, the better off you are" needs to be brought into dialogue with empirically grounded accounts opening up the paradoxes, moral economies, and ambivalences of digital patienthood. It might be fair to argue that the more information patients have (and produce) as recipients of care in chronic care infrastructures, the more urgent the question of response-ability becomes.

Concluding discussion

The turn to informational medicine and digitally engaged patients is embedding patients, as recipients of care in the Danish public healthcare sector, into digital care infrastructures. Being tied up with these infrastructures can be experienced as intrusive, boundary blurring, and associated with intensification of digital labour, and last but not least, experienced as being at odds with personal ideals and wishes for how to live a good life with chronic illness. I have used a pilot study as a small-scale intervention against the techno-solutionist assumption illustrated in the opening interview quote, where more information or data is envisioned as a route to patient empowerment and better care. This intervention is operationalised by the creation of two narrative vignettes. The first shows us how a contemporary moral economy of data-sharing is affectively charging the practice of digitally disengaged patienthood with ambivalence. Prioritising self-care through disengagement and digital boundary work over that of care for others through data-sharing, I suggest, yields further empirical explorations: What does digitally disengaged patienthood look like? And to what extent might different forms of digital boundary work be shaped by and shape contemporary patienthood? The second vignette illustrates what partial digital disconnection in a life with chronic illness can look and feel like. It shows disconnective care as a compromise, as partial disconnection and making do stand in for the desired but not obtainable full disconnection.

Questions of disengagement in and disconnection from digital care infrastructures threaten to disappoint those expectations about patient empowerment and efficiency tied up with contemporary digital welfare solutions. By bridging the fields of disconnection studies with critical digital health studies, the narrative analyses illustrate how the messy everyday reality and practice of digital patienthood and forms of disconnective care run counter with techno-solutionist visions about the provision of healthcare. As private–public collaborations within healthcare are becoming more common, the need for an ethics of response-ability for *which kinds* of data are of use and value and for *who* becomes a critical element in the delivery of digital and data-driven care. The vignettes call for further empirical studies of how, why, and where patients disconnect. With this contribution, I hope to have brought attention to one of the paradoxes emerging when patients living with chronic illness receive care in the public digital healthcare sector: The more entangled with digital technologies and the production of data healthcare becomes, the more the recipients of care – the patients – might turn towards different practices of disconnection to care for themselves. For people living with chronic illness, care is paradoxically provisioned and received at one and the same time through connection and disconnection.

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Endnotes

1. Eboks is a mailbox linked to Danish citizens' personal registration number, which enables communication between public authorities and citizens.