Long Covid: Digital Health Technologies, Patient Activism, and Illness Narratives

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There are over sixty-five million people worldwide suffering from Long Covid. The condition, though largely accepted as a diagnosis, does not yet have a legitimate status. Patient organizations have used analogue means and digital technologies to raise awareness and draw attention to Long Corvid's long-term effects. In this article, Monika Pietrzak-Franger (University of Vienna) takes a quick glance at the ways in which digital health technologies may be used in the fight for recognition and legitimation, knowledge creation, and community building. She pays particular attention to the downsides of online illness narratives and iconographies that have appeared in this context.

Disease has always been a matter of politics. While it is, for most of us, a personal event, it rarely impacts only one body: when our phenomenological relationship with the world changes, so do our interpersonal relations, with family members and smaller or bigger communities. Our salient bodies become a disturbance: in everyday practice, on the economic market, within the larger imagined community that is a nation, or the world. This is all the more the case with long-term diseases and with the contested ones which have yet to be legitimized by the medical establishment and society. Diseases as events and everyday practices are political, and so are the stories we tell about them and the images we associate with them: illness narratives and iconographies. Medical and sociopolitical histories are testimonies to their rhetorical power.

When new health conditions, such as Long Covid, appear on the horizon, they become inscribed in the traditions of treatment and representation, activating particular behavioural and representational scripts that may be empowering as well as oppressive, or – at times – both. When the appearance of such an illness goes hand in hand with a proliferation of expressive means, enabled, as in the case of Long Covid, by digital environments, the impact of such representational practices may be profound. As the first illness 'made on social media' (Callard and Perego 2021), Long Covid exemplarily demonstrates how digital health technologies may be used in the fight for recognition and legitimation, knowledge creation, and community building. At the same time, Long Covid narratives and iconographies show the shadow side of this struggle, highlighting the stigmatizing power of extant representational traditions and spotlighting the difficulties in coming to terms with the unknown condition, which become manifest in various problems in their narrativization and visualization.

Patient-made: From Contested Illness to Acknowledged Multisystemic Condition

Long Covid has been a contested illness. As the pandemic progressed, though still in its early stages, the so-called 'long-haulers' drew attention to the persistence of a number of multiorgan symptoms months after the infection with SARS-CoV-2. Similarly, a survey conducted by the UK Government's Office for National Statistics in November 2020 showed that one in five infected exhibited symptoms that lasted more than five weeks (Venkatesan 2021). Over 200 symptoms have been collected and reported by patients, ranging from recurring coughs and persistent brain fog to breathing problems and fatigue.

In the meantime, the existence of Long Covid has been acknowledged by (inter)national bodies, albeit with varying terminology. Under the entry "Post COVID-19 Condition (Long COVID)", the World Health Organization defines it as "the continuation or development of new symptoms 3 months after the initial […] infection" (WHO). While the organization has also developed a more elaborate clinical case definition of Long Covid, even this very general one testifies to the fact that the condition has been officially recognized. Many countries have also issued plans regarding its treatment. In the UK, in cooperation with Healthcare Improvement Scotland, and the Royal College of General Practitioners, the National Institute for Health and Care Excellence (NICE) published a 'rapid guideline' in December 2020 (last updated in November 2021), which offers recommendations as to how to identify, assess, and manage the long-term effects of COVID-19. Irrespective of these developments, it must be remembered that such an 'official' acknowledgement does not necessarily mean a full-fledged, cross-societal acceptance. Long Covid does not have the same 'legitimate' position as cancer or measles, in fact, for many, it still does not exist.

The speedy official acknowledgement of Long Covid may be partly due to the apparent prevalence of cases. According to latest estimates, at least 10% of those infected are subject to suffering from Covid-19 sequelae; this amounts to no less than sixty-five million individuals around the world (Davis et al. 2023). Considering the vast number of people affected, the (often) inadequate extant health provision infrastructures and the impact the condition has on work uptake, it is to be expected that both the economies and health care systems (e.g., insurance companies) will have to deal with the issue sooner or later. The way they will deal with the condition will, of course, impact the everyday lives of many; still, when handled with care, it may also serve as an impulse to change the way we think about chronic and contested illnesses, and offer a model of how to deal with them in a sustainable manner. Whatever the outcome, though, it is clear that vast resources will be needed to understand the long-term effects of Long Covid and develop necessary (healthcare) infrastructures to address these.

Be that as it may, it also transpires that the institutional (official) acknowledgement of Long Covid would not have happened, nor would it have happened so quickly, were it not for a number of patient (activist) groups who drew attention to its existence. In fact, the NICE guidelines acknowledge their work in discussing the choice of nomenclature, when they say that "[t]he panel recognized the significant progress made by patient groups using the term 'long COVID'" (NICE 6). Likewise, the first version of WHO's clinical case definition of Post-COVID-19 Condition is said to have been "developed by patients, researchers, and others, representative of all WHO regions" (WHO 2022). Likewise, researchers across disciplines have highlighted the importance of including patient experience in the processes of knowledge creation as well as policy making.

Indeed, patient-researchers have made claims to playing the key role in making the illness visible. Felicity Callard and Elisa Perego (2021) suggest that "[p]atients collectively made Long Covid". It is, they continue, "the first illness created through patients finding one another on Twitter: it moved from patients, through various media, to formal clinical and policy channels in just a few months" (Callard and Perego 2021). Undeniably, social media channels, as part of larger digital health technologies, have proved central both in patient activism and in the processes of knowledge creation in this context.

Digital Health Technologies and Patient Activism

Digital technologies have transformed the ways we perceive and practice health. The evolution of the Internet – from Web 1.0 that enabled storing, sharing and viewing of information to Web 4.0 that has become a highly networked, regulatory 'Internet of Things' – went hand in hand with the evolution of digital health technologies. Today, e-health, also known as electronic health or digital health, and referring to the use of technology and digital communication tools to manage and improve healthcare delivery and outcomes, has become part of the essential health provision infrastructure in many countries. While still in its infancy at the turn of the century, e-health has continually developed further, gaining added impetus with the onset of the pandemic.

The "e" in e-health does not simply imply "electronic" but also refers to a number of expectations that Gunther Eysenbach appositely lists under "The 10 e's in 'e-health'": "efficiency", "enhancing quality", "evidence-based", "empowerment", "encouragement", "education", "enabling", "extending" (2001). What this list irrefutably demonstrates is the fervent hopes that researchers drew from and associated with those transformations in their early stages. Indeed, Eysenbach considers the concept of e-health not only as signalling a technological revolution but also as a term that characterizes "a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology" (2001). And indeed, a lot has changed when it comes to healthcare provision systems around the world, although, to be fair, the pandemic has revealed the in-built problems and inequalities within such systems as well as laying bare the fault lines of such 'globalized', 'networked' thinking. Merrill Singer's concept of a "syndemic" (2009) has rightfully been revived to draw attention to the intertwined epidemics and crises that we are experiencing at the moment.

Still, in dystopian times, utopian visions are necessary to fathom any kind of future. It is therefore not surprising that digital health technologies have been used to pursue activist goals, irrespective of the dangers they may harbour. Digital health technologies span a broad range of practices and products ranging from telemedicine, mobile health apps, wearable devices, to health information exchange platforms, and social media. Amongst these, online environments (especially social media) have been seen as particularly expedient and enabling not only when it comes to information-seeking but also as concerns the generation of knowledge, fundraising for research, and advocacy for changes in health practices and policies (Petersen 2020).

Still, what cannot be neglected is the exploitative potential of said environments: the emergence of the 'quantified self' (self-tracking and self-monitoring), 'datafication' (transformation of various aspects of everyday lives into analyzable data), 'dataveillance' (monitoring of people's behaviour through digital data), misinformation or commercialization of evidence. The resultant "digital patient experience economy" has been seen as valorising "big data, the discourse of sharing and commercialization of affective labour" (Lupton 2014, 856). Digital environments have also been associated with gross infringements of privacy and civil rights and high potential for discrimination and stigmatization. This notwithstanding, they have been regarded as crucial to the generation and circulation of counter-knowledge, recontextualization and problematization of professional positions, re-evaluation of extant healthcare pathways, and the growth of research-relevant digital repositories of (experiential) data and evidence (Whooley and Barker 2021; Lindén 2021; Callard and Perego 2021).

Patients have made ample use of online environments and digital media. Patient activism (or advocacy) broadly refers to any endeavour (individual or collective) that aims at making visible and legitimating an illness (or condition), addressing the necessity of its proper treatment, or exposing inequalities of health provision infrastructures and improving standards of care. Ranging from grassroots actions to formal participation in policy making processes, patient activism has long been in existence. While the work of the ACT UP collective (HIV/AIDS activism) or breast cancer groups has been well documented and researched, the history of medicine is full of various actions directed against particular modes of treatment or medical establishment; take for instance, late nineteenth-century patients' self-publication and distribution of leaflets against internment in psychiatric asylums in Germany.

While the 'Long COVID movement' displays characteristics of older types of patient activism, it also draws on newer tendencies in digital advocacy. Social media and the internet have changed the way patient movements operate (Petersen et al. 2019; Schermuly et al. 2021). While few in number, studies of patients' digital activism draw attention to the new opportunities that digital technologies offer (e.g., co-production of knowledge, enactment of chronic diseases;

cf. Gonzalez-Polledo and Tarr 2016). Various proponents of digital media and mobile application technologies (policy makers, technology specialists, and clinicians) see such environments as enabling and empowering to individuals and communities alike, because they provide, for instance, better access to information and, with that, can help patients make more informed choices.

Hence, recent years have seen an intensification of critical discourses about patient engagement and empowerment, and about the so-called "bio-digital citizenship" (cf. Lupton 2018), where the latter is characterized by "the entwining of biologically based identities and digital-based practices" (Petersen et al. 2019, 481). As 'prosumers' or 'produsers' (cf. Bruns 2008), patients have been viewed as empowered by digital health technologies, which allegedly offer them "choice and control" when it comes to self-management and decision making (Lupton 2018, 40). At the same time, various scholars of digital media have signalled the problematic character of such language. For Lupton, for instance, the notion of a "digitally engaged patient" is part of a neoliberal orientation to patient care, which sees individuals as "ideally willing to seek relevant health and medical information actively, engage in their own healthcare and take up behaviours that preserve and maintain good health, in the attempt to shift the burden of such responsibilities from the state to the individual" (2017, 41). Such discourses "reduce health problems to the micro, individual level" and therefore fail to "identify the broader social, cultural and political dimensions of ill health" (Lupton 2017, 43). They also ignore the downsides of the datafication of human lives. This notwithstanding, the 'Long Covid Movement' has made ample use of online environments to raise their cause.

Long Covid Activism and Initiatives: Recognition, Research, Rehabilitation

As early as in May 2020, the #LongCovid hashtag appeared on Twitter (Perego and Callard 2021). In Great Britain, LongCovidSOS and LongCovidScotland – now both registered charities – began their work; the former in July 2020. In the USA, Fiona Lowenstein, journalist and founder of the health justice organization Body Politic, formed a support group after experiencing prolonged health problems following her COVID-19 infection. In Austria, the Long Covid Austria initiative gained ground in January 2021 and, in September of the same year, Long Covid Europe (LCE) brought together partner patient organizations from across the continent.

"Recognition, research, and rehabilitation" are the three goals that have become the focus of these and similar groups (LCE, LongCovidSOS). Apart from the official recognition of the condition, its definition, and incorporation into the CDC (Centers for Disease Control and Prevention) register, 'recognition' also refers to the debates around the condition's naming, its acceptance as a legitimate illness by individual medical practitioners, insurance companies, the general public, and by employers. It also denotes an acknowledgement of the importance of patients' perspectives in decision and policy making. Amongst the many problems pointed out by patient organizations, the currently major one remains their concern with the psychologization of the condition on many levels: be it by individual doctors, across media reports, or in the public opinion.

If, as a goal, recognition has many dimensions, so does research and rehabilitation. Writing in May 2020, Lowenstein explains the rationale behind the collective action of the rapidly growing international group:

> *[…] it became clear that others were desperate for information to understand their experience. In the absence of comprehensive, up-to-date information from health authorities, the support group has allowed people living with or recovering from the disease to discuss lesser-known symptoms, crowdsource best practices from health authorities around the world, and arm against medical bias that affects marginalized populations. (Lowenstein 2020)*

The lack of information about the condition and about its mid- and long-term effects was one of the reasons behind the creation of many such groups and the communication between them.

In the UK, government and funding bodies have allocated ample resources for Long Covid research. The Department of Health and Social Care reported in July 2021 that another fifteen Long Covid research projects would receive government funding (amounting to almost twenty million pounds) through the National Health Institute for Health and Care Research. Next to focusing on a better understanding of the condition and its long-term effects on individuals and communities, the funded projects aim at evaluating the efficiency of available services, identifying effective treatments, improving self-management and monitoring of patients, and "better integrating specialist, hospital and community services for those suffering with Long Covid" (Government Digital Service 2021). In Austria, to my knowledge, there are only about a dozen small-scale initiatives that deal with the issue, be it our interdisciplinary Post- COVID-19 Care project, or the search for particular biomarkers that could be associated with Long Covid (Kovarik et al. 2023). In many of such projects, Long Covid patients are mere 'study objects' as part of a traditional research design. In the meantime, and on many fronts, Long Covid patients demand that research be made *with* and not only *on* them. Such voices are very much in line with the spirit of citizen science, which involves members of the general public in the execution, and in fewer cases, in the co-creation of research designs.

Just like in the case of research, when it comes to rehabilitation, the major problem initially was lack of knowledge about the condition itself and, as a consequence, the resort to, for instance in Austria, rehabilitation programmes that were intended for other diseases (e.g., cardiovascular or pneumological problems). Whilst the importance of 'pacing' is recognized today, rehabilitants' refusal, mostly due to fatigue, to pursue certain activities led, time and again, to accusation of non-compliance and had impact on future prescriptions (Alexa Stephanou, personal communication, 2nd November 2022). In the UK, the NHS has published a 10-step action plan, supported by ninety million pounds in 2022/23, to improve Long Covid services (NHS England n.d.). "Your Covid Recovery" is one element of the package aiming to "boost" NHS support for patients. It is a rehabilitation programme that is "digital, interactive, and tailored" (ibid.). Its aim is to complement the services of specialized post-Covid centres, ninety in number, which provide access to diagnosis, treatment, and rehabilitation (ibid.). This NHS plan includes patient-involvement and reliance on their lived experience as it also directly addresses patients and provides guidelines about how to get involved in research (NHS England 2022, 30-31).

While relatively swift, the evolution of these services still took time. This said, a number of bottom-up initiatives for and by patients began to sprout early in the pandemic. In the UK, the "ENO Breathe" programme was called to life by the English National Opera in cooperation with clinicians at Imperial Heathcare NHS Trust. This online programme uses singing techniques to improve wellbeing and quality of life for people with respiratory problems after COVID-19 infection. Up to April 2022, around 1000 people participated in the programme, and a clinical trial of 150 participants found an over 10-point reduction in breathlessness (Imperial College Healthcare NHS Trust 2022). The website of ENO Breathe also amasses participant testimonies (English National Opera n.d.). Currently, they are working directly with many Long Covid Service Centres across UK in which doctors prescribe their singing- and breathing-based programme directly to Long Covid patients (Jennifer Davison, personal communication, 10th February 2023).

Not everywhere have such co-operations been implementable. In Austria, although a similar pilot project was initiated in 2021 (29th September – 10th November) under the name "Aufatmen", its expansion has not been possible. In the pilot project, 49 Long Covid sufferers met for six weeks (four online and one onsite group). At the same time, they had access to a website with music videos, teaching instructions, a forum and a weekly programme. Project participants have reported a noticeable improvement of their fitness and their well-being (Edith Wolf Perez, personal communication, 21st February 2023). The pilot project was sponsored by and developed in cooperation with the Bundesministerium für Soziales, Gesundheit, Pflege und Konsumentenschutz, City of Vienna, the Porticus charity, the Theater an der Wien and Wiener Konzerthaus. In order to expand the project, its initiators have contacted Austrian private insurance companies and social insurance agencies. The reactions have been varied but never positive: either the organizations claimed to have their own rehabilitation programmes, or the decision processes have been long-lasting and brought no outcomes. As other endeavours to fund such an extension of the pilot programme have also proved unsuccessful, any large-scale development has been out of the question. This said, the Aufatmen programme has not stopped. As I write, in February 2023, the fifth edition of the programme is

Aufatmen - Ensemble, © Gabriele Schacherl about to begin with roughly 120 participants who pay for their participation. After the end of the pilot-phase of the Aufatmen project, the group also launched a "Weiteratmen" sing-initiative. Many early participants continue to be part of it (Edith Wolf Perez, personal communication, 21st February 2023; Arts for Health Austria n.d.).

The mobilization of Long Covid patients in the fight for recognition, research, and rehabilitation has been extraordinary. With the press popularizing the discussion, their voices have been heard across media channels. Still, patients continue to call for more attention and involvement. The updated website of Long Covid Scotland bears the slogan "See us. Treat us. Study us." This demand is both direct and aggressive. Fifty-five thousand patients (members of Long Covid Scotland) want the medical gaze to be actively turned on them and guided by them. The patient-position empowers them to demand attention, cooperation, and further research. Long Covid Scotland has established partnerships with universities, the government, and Social Care Alliance Scotland (Long Covid Scotland n.d.). While, in Austria, patients have contributed to the work of some Long Covid Centres (AKH Post-Covid-Ambulanz), and participated in discussions with insurance companies regarding the future workplace, they have, at the same time, been excluded from the governmental task force (Alexa Stephanou, personal communication, 2nd November 2022). This said, in Austria and elsewhere, Long Haulers have been enabled, by social media and their advocacy work, to shape the narrative of Long Covid.

Long Covid Illness Narratives and Iconographies

Long Covid narratives have become increasingly visible in online environments. Social media channels have been filled with illness narratives; established platforms, like the *Guardian,* have also reacted to this proliferation of stories by launching the "Living with Long Covid" section; universities have opened digital spaces for patient stories. Whilst Twitter has been regarded as the social media channel that helped made Long Covid, Facebook served as a space for the formation and communication of Long Covid groups, and Instagram and TikTok made visible the particular iconography of the condition. Long Covid charities, support groups as well as influencers and celebrities have used social media to report on their everyday struggle, give advice, and inform about the latest developments but also to vent their frustration.

An early study of Long Covid patient narratives (employing narrative interviews and focus groups as a method) has shown that, in contrast

Long Covid Care Discussion with Prof. Dr. Mariann Gyöngyösi (AKH Post-Covid-Ambulanz), Sarah Wolf, MSc (AIHTA), Edith Wolf Perez (Projekt "Aufatmen"), Alexa Stephanou and Alexandra Marton-Krenek (Long Covid Austria), 16 Jan. 2023, University of Vienna, ©Tamara Radak

to the official biomedical narrative, patients depicted the condition neither as short-lived nor as limited to the respiratory system. Further inconsistencies emerged: in patient narratives, the protean character of the illness was stressed and the dichotomous perception (severe vs. mild) of the initial infection and its effects was called into question. The patients emphasized the "strangeness" and "weirdness" of their state (Rushforth et al. 2021, 4). They described the condition in terms of the disruption of their lives, using before-after constructions to emphasize the stark contrast between what they were able to do before and after being infected. Recognizing the narrative construction of the patient experience, the study identified common traits of the stories as: a "disrupted chronology", frustrated trajectory (of recovery), and a common plot twist (bettering of one's condition followed by a relapse or new, unexpected symptoms). The frustration with such a course found vent in immobility rhetorics, with metaphors of going back and forth and being stuck used to describe the confusion and helplessness of the interlocutors (Rushforth et al. 2021, 5). The stark contrast between the medical and the collective, bottom-up narrativization of the condition as experienced, demonstrated the mutability of the illness and challenged its biomedically established pathology (Rushforth et al. 2021, 7). Soon, a number of stories appeared across media channels that highlighted 'medical gaslighting' as well as stigmatization and discrimination practices, and a general lack of understanding from the public (cf. Au et al. 2022).

It seems as though, in the meantime, a much broader public has become interested in such stories. Were it not the case, established news venues would hardly decide to publish them. With a particular audience and aim in mind, they have contributed to the visibility and proliferation of Long Covid narratives. These considerations precisely have also impacted the selection and type of narrators. Whilst the patient experience is given centre stage in these accounts, they are in line with the overall political agenda of the platforms. In the early *Guardian* accounts, for instance, a notable predominance of female, white, middle-class heterosexual narrators goes hand-in-hand with an underrepresentation of stories of people with lower socio-economic status, ethnic minorities, migrants and asylum seekers as well as the elderly and disabled (Lange in press). Although the first or third person accounts take pride of place, they are flanked and legitimated by 'expert' opinions. Told from an *in-medias-res* position, the narratives are suspended between what Arthur Frank called the "chaos" and "restitution" narrative types (Lange in press). Almost infallibly, they dramatize the rupture that the infection constituted for the narrators; they offer a dualistic chronology of life before and after COVID-19. By setting off with the moment of COVID-19 infection, they also invariably biologize the condition. This biologization also acts as a legitimating factor. Other such factors include, but are not restricted to, the emphasis on the Long Haulers' almost superhuman productivity in their pre-COVID-19 lives (hyperbolization), their discipline, their healthy lifestyles, i.e., their willing participation in the neoliberal economy. The minute detail of the course of the illness, attention to the variety of symptoms, their intensity and their temporality emphasize not only the struggle that they have endured but also, through this focus, gives them the moral high ground to talk about it, and, ultimately, legitimate their stories (Lange in press). Rhythmic, sinusoid-like, open-ended with non-linear emplotments, they testify to the difficulties that patients have in finding an adequate vehicle for their experience.

Social media are 'better-suited' in this respect in that they help evade, even discourage, the logic of narrative linearity. With their affordances and their inbuilt relational architecture (hashtags, inter-platform connectivity) as well as with the practices they encourage (frequency of posts, reactions to other posts, re-posting, etc.), they, in fact, emphasize fragmentation, serialization, and open-endedness. Rhythms, recurrences, and revisitations become the grammar of such stories. These 'flash', mini-expressions allow a conceptualization of the condition in its complex connectivity and layered temporality. In this way, they appear more adequate for registering the *in-medias-res* position of the narrators, and their anchoring in the here-and-now. Irrespective of the formal differences, many of these attempts at giving expression to the experience of Long Covid show a tendency towards temporal dichotomization of the condition and hyperbolization of the able-bodiedness before COVID-19 as a legitimation strategy along with the propensity to identify with the exigencies of neoliberalism, and notions of 'good citizen' and 'good patient'.

These validation strategies are, time and again, undermined by the visuals that 'illustrate' them. Whilst the *Guardian* narratives do their best to legitimate Long Covid, over and over, the accompanying visualizations call them into question by activating long-standing traditions of illness iconographies. What emerges is a pattern of swooning women, with historical links to hysteria, feminization of disease, and, with that, to the possible overreaction to or performance of illness (Lange in press). While, clearly, there exist other tendencies as well, the frequent retweeting and hyperlinking of such (often stock) images creates a particular representational pattern, which inadvertently links Long Covid accounts to practices of malingering and simulation.

Similarly, Instagram accounts such as '@NotRecovered' or '@nichtgenesen', perpetuate this association. With its aim to give a face to #LongCovid and related conditions (Wir geben #LongCovid, #ME/CFS und #PostVac ein Gesicht!, Nichtgenesen n.d.), they consist of a series of black-and-white portraits, mostly selfies, with the name, age, place of residence, occupation and information about the onset of illness/the person's inability to work. Front close-ups of their faces show them either resting on pillows, or placed against barely distinguishable backgrounds, earnestly looking into the camera. The schematic information, uniformity of representation, and the black-and-white – mourning – aesthetic communicate the sheer numbers of the affected, while, at the same time, purposefully or not, reductively defining them through their inability to work – their loss of productivity. By reducing Long Covid sufferers to this one characteristic, such representation positions them within the 'swooning' tradition and frames them – inadvertently so – as malingerers who do not conform to neo-liberalist ideals of productivity.

The Politics of Digital Health Practices

The online existence of Long Covid is symptomatic of the mixed blessing that digital health technologies have been for our understanding and practices of health and illness. Whilst such spaces offer an unprecedented access to information and mobilization possibilities, they also activate various traditions of stigmatization. As they rely on persistent representational scripts, they, often inadvertently, also subscribe to oppressive histories. Long Covid patients justify their hyperbolized narratives and their dichotomic temporalities by their attempt to counteract reactions of incredulity they have met with. Whilst entirely legitimate, these strategies are also fraught with many problems as they adhere to the binary logic of explanation. Still, what else can they do, if they are constantly confronted with disbelief? Here, like in many other contexts, narratives are a matter of life and death – or, at least, of a proper treatment.

We have certainly gained a lot with the advance of digital health technologies. Still, if nuance and detail disappear, we shall remain trapped in ostracizing narrative and representational regimes that are tightly interwoven with digital health practices. Like diseases, illness narratives and iconographies are a matter of politics. This should be enabling to us all. Next time we retweet or like anything, we may consider the impact of such a practice. Or, we may begin to spin a new story or paint a different picture: as clumsy as such scribbles may seem at the start, they may turn into full-fledged, visionary landscapes one day.

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Endnotes

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