



OPEN ACCESS

Postdigital health practices: new directions in medical humanities

Monika Pietrzak-Franger

Correspondence to

Professor Monika Pietrzak-Franger, Department of English and American Studies, University of Vienna, Wien 1010, Austria; monika.pietrzak-franger@univie.ac.at

Accepted 2 October 2023

Published Online First

20 November 2023

ABSTRACT

Digitalisation has changed the way we understand and practice health. The recent pandemic has accelerated some of the developments in digital health and brought about modifications in public access to information. Taking this into consideration, this programmatic paper sets the stage for and conceptualises postdigital health practices as a possible field of inquiry within medical humanities. While delineating some central aspects of said practices, I draw attention to their significance in contemporary strategies of knowledge production. Spotlighting online environments as the point of ingress for the analysis of these practices, I propose three possible foci of critical and methodological engagement. By spotlighting the serialisation, multimodality, and transmediality of such environments, I argue, we have a chance to both augment and go beyond the field's long-standing preoccupation with narrative, attend to various strategies of communicating illness experience, and re-frame them within larger questions of systemic inequalities. On this basis, and taking as examples COVID-19 and Long COVID, I sketch some of the directions that future strands of medical humanities may take and some of the questions we still have to ask for the field to overcome its own biases and blind spots.

POSTDIGITAL HEALTH PRACTICES: NEW DIRECTIONS IN MEDICAL HUMANITIES

The COVID-19 pandemic has been declared a 'teachable moment' for politics, policies, societies and sciences alike (Hastings 2020). It has also been seen as a chance to rethink the trajectories and self-image of the humanities in general and medical humanities in particular. Calls were issued to expand, re-scale and re-narrate medical humanities, and to demonstrate the applied value of the field (Lewis 2021; Ostherr 2020). The wish to go beyond the unpacking of various sociocultural framings, systemic inequalities, and biased narratives went hand in hand with the impulse to think about the field's translatory and interventionist potentialities—areas of application that would include more than university teaching. In this context, various types of (strategic) alliances, interdisciplinary exchanges and theoretical/thematic turns suggested before the pandemic (eg, Whitehead and Woods 2016, Johnstone 2018; Ostherr 2019) appeared to be more valid than ever.

Still, what has only marginally been present—in at least to my knowledge—in the postpandemic programmatic reflections is a call for a systematic attention to digital environments. While public health and communication scholars, sociologists

and bioethicists have focused on digital transformations of healthcare, research in medical humanities (especially anchored in literary, media and cultural studies) only cursorily extends to these terrains. Apart from the championing of 'critical digital health studies' (Lupton 2018) in Australia, individual calls to mobilise digital humanities in the service of health and medical humanities (Ostherr 2019), and punctual studies of 'contagion media' (Ostherr 2020; eg, Keidl *et al.* 2020; Pietrzak-Franger 2021a; also see other papers in this Special Issue), comparatively little notice has been taken of the ways digital environments impact health and illness today.

Already in pre-COVID-19 times, digital platforms and technologies changed the way we understand and practice health. They also significantly altered healthcare. The pandemic has accelerated these developments as it has also brought about modifications in public access to information. It has once again emphasised the role of media (technologies) in the construction and communication of knowledge about health and illness. While describing an already familiar phenomenon, the concept of the 'infodemic' (Ghebreyesus 2020) has emerged to mark the speed and the volume of (mis- and dis-)information, often leading to confusion and 'risk-taking behaviours that can harm health' (Ghebreyesus 2020). At the same time, comparatively little, at le

ast in the context of medical humanities, has been said about the concomitant 'visiodemic' (Pietrzak-Franger (2021a)) or about the use of particular (digital) technologies in the processes of knowledge construction and communication in postdigital times. Further research is needed into the ways in which what I call *postdigital health practices* activate *different* modes of expression and strategies of mediatisation in order to articulate personal and collective experiences of illness and well-being (cf. also, Fung *et al.* 2020; Mazanderani, Locock, and Powell 2012).

This programmatic paper sets the stage for and conceptualises postdigital health practices as a possible field of inquiry within medical humanities. Spotlighting online environments as the point of ingress for the analysis of these practices, I see them as chief sites for the articulation and communication of subjective evidence and experiential knowledge. In fact, I would like to argue that patient accounts have become tightly interwoven with the digital and therefore can no longer be treated as belonging to a realm separate from traditional articulations of illness. Considering this, I propose a tripartite model with the help of which to study



© Author(s) (or their employer(s)) 2023. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

To cite: Pietrzak-Franger M. *Med Humanit* 2023;**49**:503–510.

such accounts—a model rooted in serialisation, multimodality and transmediality studies. I argue that by attending to postdigital health practices we have a chance to both augment and go beyond the field's long-standing preoccupation with narrative, spotlight various (new) strategies of communicating illness experience, and re-frame them within larger questions of systemic inequalities. Systematic attention to postdigital health practices and illness accounts that they generate is bound to yield further insight as to how we conceive of health and illness, how we communicate in this context, and how we act on those conceptions and representations. On this basis, I sketch some of the directions that future strands of medical humanities may take and some of the questions we still have to ask for the field to overcome its own biases and blind spots.

KNOWLEDGE PRODUCTION AND DIGITAL ENVIRONMENTS

Online environments are central to health-related knowledge: how it is produced, disseminated, (de-)legitimised and (de-)valued. As early as 1999, sociologist Michael Hardey saw the internet as the 'site of a new struggle over expertise in health that will transform the relationship between the health professions and their clients' (Hardey 1999, 820). With changing digital infrastructures over the last 30 years—from Web 1.0 (storing, sharing, viewing) to Web 4.0 (a highly networked, self-regulatory system; the Internet of Things)—everyday health practices have changed as well. The concomitant evolution from Health 2.0 to Health 4.0 has likewise transformed the modes and forms of users' engagement, along with their agential and exchange possibilities: from medical-information-based websites, personal blogs, opinion and discussion forums (Health 2.0), to a variety of social media platforms (Facebook, Reddit, Twitter, Instagram, TikTok), wearables and apps (Health 3.0), to, finally, Big Data reservoirs, AI configurations and virtual space potentialities (Health 4.0). Users can now monitor their mental states by using such mood trackers as *Moodfit* while Wearables like *fitbit* or smartwatches allow them to supervise and optimise their somatic functions, and apps like *Headspace* give them mental health advice. Social media channels offer platforms for the exchange of health-related information and personal experience (eg, the Facebook self-help groups of Long Covid SOS and Long Covid Europe, or Endometriosis UK), as do various internet opinion and discussion forums. Recently, the UK's National Health Service (NHS) has developed *Wysa*, an AI chatbot that understands natural language and emotions and can interact with patients waiting for traditional psychotherapy.

Latest studies that focus on such developments have highlighted how such environments have complicated the production and circulation of knowledge. They have drawn attention to online users' amalgamation of professional and lay knowledge, to various strategies of legitimisation of lay experience (Au and Eyal 2022; Bellander and Landqvist 2020; Lindén 2021), and to the power of net-activists' counterknowledge. They have also stressed the resultant recontextualisation and problematisation of professional positions, re-evaluation of valid healthcare pathways, and the growth of research-relevant digital repositories of (experiential) data and evidence (Callard and Perego 2021; Lindén 2021; Whooley and Barker 2021). This aggregation of large data archives and facilitation of peer support have been seen as potentially able to reshuffle extant value systems and power structures, and with that, also healthcare provision, research and policy making (Lupton 2014).

Simultaneously, what has been pointed out is the exploitation potential intrinsic to digital health environments (eg, the

emergence of the quantified self, datafication, dataveillance, misinformation and commodification of evidence), the resultant 'digital patient experience economy' and the way it valorises 'big data, the discourse and ethic of sharing and the commercialisation of affective labour' (Lupton 2014; Lupton 2016, 856). Furthermore, various problems relating to issues of data security, privacy and civil rights have been identified, along with fundamental shifts in self and social relations, in autonomy, and solidarity (Lupton 2016; Lupton 2019; Prainsack 2022; Ruckenstein and Pantzar 2015). Attention has also been drawn to online environments' potential for discrimination, stigmatisation, and production of shame and guilt (Beer 2016; Neff and Nafus 2016; Whitson 2013; Whitson 2014) as well as to a widening of the digital divide and, with it, uneven access to health services across socioeconomic groups (Gallistl, Seifert, and Kolland 2021; Lai and Widmar 2021).

In the context of the pandemic, online environments (especially the social media) have facilitated the articulation and sharing of experience. Long COVID has provided a further appraisal of this kind of subjective evidence (Callard and Perego 2021; Rushforth *et al.* 2021), that is, records of patients' sensorial, cognitive, valuational and affective accounts of their illness experience (Greenhalgh 1999). While variously termed (eg, illness narratives, experiential knowledge, patient-specific knowledge), subjective evidence has been surveyed with special focus given to its use in patient activism (Epstein 1995; Rabe-harisoa, Moreira, and Akrih 2014; Roth and Gadebusch-Bondio 2022) and self-help groups (Borkman 1976), its role in identity creation (Mazanderani, Locock, and Powell 2012), its status and acceptance by the medical community as well as the communication strategies used (Atkinson *et al.* 2021; Blume 2017; Jones, Jallinoja, and Pietilä 2021).

Still, the expressions of subjective evidence adhere to rules other than the ones we know from *les lettres*, even as the category of literature has expanded and opened up to the rules of digital production. Online environments favour episodicity over narrative coherence and linearity. The selves—ill or not—produced, communicated and curated online are selves that are composed of small chunks of information: they are makeshift, fragmented, incoherent, multimodal, plurivocal, connected, relational and interactive (c.f., Bamberg, Demuth, and Watzlawik 2021; Giaxoglou 2022). Siding with Stella Bolaki and others, I would like to call—if the call is indeed still necessary—for a systematic examination of what online environments and their affordances enable in terms of the representation of subjective evidence. Here, though, I would like to further the argument and ask not only 'how such [online] narratives do their work' (Bolaki 2016, 212) but also what forms (narrative or not) and modes of expression such environments make possible: how can we—as scholars—adjust our critical apparatus and methodology to account for these forms and modes?

It is my contention that studying online environments and the renditions of illness they host gives medical humanities scholars both the opportunity to reconsider the narrativisation of illness and look at other modes of expression that go beyond the narrative. In this context, it is worth attending to what I regard as the three major characteristics of online environments that favour the curation, active participation in, and shareability of illness experience, namely: serialisation, multimodality and transmediality. In what follows, I draw attention to these characteristics, offer a model-reading based in serialisation, multimodality, and transmediality studies and show how such a reading expands and transforms the practice of medical humanities

SERIALISATION: CHRONICITY UNBOUND

Online environments undermine the illusion of a linear narrative self. They call into question our ability to narrativise illness. In this tweet from 27 March 2020, the beloved British children's author and scholar, Michael Rosen, records some of his prediagnostic COVID-19 symptoms, which would then worsen so much that he would have to be put into an induced coma to survive:

Day 12. The year's seasons roll by in a night: sweats, freezes, sweats, freezes. Wondered whose mouth I had: I didn't remember it as made of sandpaper. Water is as good as ever. (Rosen 2020)

This tweet also opens his book of poems *Many Different Kinds of Love* (Rosen 2021a) and sends us to the *Guardian* poetry column entitled 'I am not who I was' – Michael Rosen on surviving Covid - extract' (Rosen 2021b). Strikingly, since Rosen's Twitter activity stops between 27 March and 9 June of the same year, his coma is recorded through a period of silence, broken by infrequent posts by his wife Emma-Louise. On Twitter, then, silence marks the severity of his state within the trajectory of the disease.

Importantly, in the collection of poems, an attempt is made at reconstructing the missing narrative. The main narrator's disappearance (his unconscious state) is substituted by witness accounts. Next to tweets, Rosen's *Many Different Kinds of Love* is a book of short (visual and written) forms; it combines email correspondence, letters, poems, multiauthored intensive-ward-diary entries, and drawings to recount the author's experience of COVID-19. Here, the COVID-19 and post-COVID-19 world is characterised by a series of fragments that can only be brought together with a lot of effort. It is marked by a variety of timelines and blurred chronologies (Rosen 2021a, 151), new temporality of bodily (mis)functions, medicinal regimes and habits (176, 192), a novel 'bit-by-bit' coming to terms with reality (147), an emphasis on the '-ing' in 'recovering' (178), where going shopping feels like a 'longterm objective' (138). The narrative within each section is no more than a sequence of ordinary events that need to be collected and propped up to create the illusion of a moving action. The narrators and the addressees change. The narrative break is filled out by the plethora of voices of those who came to care for Rosen—a collective effort of many narrators: nurses, GPs, physiotherapists, family. They offer unconnected, episodic snapshot observations of his state. It is only after preselection and careful arrangement that they provide a timeline and narrative of his comatose state.

On Twitter, the aforementioned tendency to narrativise—to construct narrative arches, to identify types of narratives, to develop their spreading typologies—gives way to a series of episodic forms. In the first place, they draw attention to themselves, and simultaneously, resist the impulse to narrativise that the collection of poems is built on. What is given volume in the punctual concentration and brevity of online posts is the 'tortured temporality' of illness and chronic pain: 'the affective strain of moments of suffering, demanding attention to particular episodes of agony without taming these within a story of personal transformation or enrichment' (Wasson 2018, 109). As a synecdoche of social media, Twitter offers precisely that. It exemplifies online environments' unboundedness when it comes to the articulating, chronicling, and curating of illness in general and chronic illness and pain in particular.

It does so on two levels: first, on the level of the expression, whereby tweets mark both the singularity and, through their serialisation, the multiplicity of those moments of suffering. It

augments their significance through repetition. In this process, it jumbles chronologies and temporalities. Due to its interactive nature, linking threads and architectural connections with other platforms, Twitter favours analepses and prolepses. Through (commented) re-tweeting, liking and hashtagging, past symptoms or stages of recovery are rushed back into the presentism of new tweets. Illness thus articulated is an illness devoid of set vectorality. It is a state of multiple temporalities; among them, the temporality of the symptom, of its articulation (or not), of its return, of the hope of recovery, of care, of the preillness self, of the others' recognition and acknowledgement.

The second plane on which Twitter, and online environments, counteracts the narrativisation of illness is on the level of reading. It encourages a *reading in instalments*: chronicity not only enfolding but also 'received' in 'real' time.¹ On 21 March 2020, Rosen tweets, 'God yes. Tongue looks like an andouillette and apart from a grape, lemon tea, and orange everything gets turned into metallic sick. First day not though.' (Rosen 2020b). In June, he continues, 'Physio, dearest Emz?! They're teaching me how to walk. And my legs don't want to' (Rosen 2020c). Accustomed to this particular mode of reading, and in retrospect, we have no problems imagining a narrative arch here. Still, the nature of the platform can teach us to suppress this impulse and learn to read differently.

By attending to the episodic character of illness experience online, medical humanities scholars can shift the emphasis away from narrative and towards other forms of expression that are neither linear nor teleological. By doing so, they have a chance to expand the catalogue of the modes of being ill and attend to marginalised voices. In 'Before Narrative: Episodic Reading and Representations of Chronic Pain', Sara Wasson shows the value of the 'episodic reading'—attending to the fragmentary—by arguing that such an approach would not only allow to multiply 'alternative illness stories,' but also make 'space for story that does not fit the expected form of 'story' at all' (Wasson 2018, 106–7). In this way, what can be focused on is the 'richer vocabulary of temporality' (107) that chronic pain requires in its 'recalcitrance to cure' (107). Already in *On Being Ill* (1926), (Woolf 2012), famously, complained about the inability of the novel—as a genre—to hold the 'uneventful' narrative of illness. With their emphasis on serialisation, online environments provide a fitting repository for the expression of chronic pain (cf. eg, Gonzalez-Polledo and Tarr 2016). It is therefore worth considering them as sites where we can learn about strategies of representing illness in general and chronic illness in particular.

With the aforementioned emphasis on episodicity, seriality, multiple temporalities and reading in instalments, online environments potentially provide not only a platform for a novel articulation of chronicity, they can also teach us, as (medical) humanities scholars, to expand our faculties by going beyond the reading for plot or narrative. Trained in episodic reading or reading in instalments, we might also come back to and reconsider more traditional forms and genres and rethink non-narrative expressions of illness (chronicity) in fiction and life-writing. All in all, online environments can help us reconsider the manifold expressions and temporalities of suffering, along with enabling a complex look at the networks that they are bound to and encourage.

MULTIMODALITY: A NOVEL INDEXICALITY OF ILLNESS

Online environments also spotlight the multiple modes in which illness can be expressed. A more stringent attention to these modes of articulation enables medical humanities scholars not

only to go beyond the textual/narrative tradition (and the narrative mode of reading) but also to make case for the importance of the expressions of illness that have been critically underprivileged. What is more, as online environments *are* multimodal environments, interpreting them only through the lens of the written word is both limiting and distorting in that it ignores both various types of (self-)expression of illness along with multiple representational traditions, many of which continue to be stigmatising.

Articulation of illness is multimodal, as is the communication of knowledge about it. In this context, multimodality refers to the plurality of semiotic modes involved in communication, which are culture-, time- and medium-specific (Kress 2010, 79, Kress and van Leeuwen 1996, 35). Both types of processes are hinged on various sign systems—from verbal and written expressions to visual, gestural, acoustic modes, and so on. While this has always been the case, it has seldom been recognised due to disciplinary and cultural privileging of the written word. For instance, learning to recognise symptoms of infectious diseases in the late nineteenth century entailed not only writing and reading of case histories, it also included demonstrations on living patients, and the comparative study of various illustrations (drawings, lithographic prints, hand-coloured photographs). Publics read about diseases in novels, heard about them from their acquaintances, saw them enacted in theatre or heard them preached about in public lectures and sermons. This said, neither the depiction of symptoms nor the articulation of one's experience of illness has ever been an easy task. Not every symptom can be communicated through language (or any other available mode), nor are media limitless when it comes to their representative function. Formed by centuries-long traditions and transformed by the appearance of ever new media, they seldom offer all-encompassing 'representational' means for the experience of illness. This is most especially the case when illness is 'invisible' (Pietrzak-Franger 2021b; Pietrzak-Franger 2017; Pietrzak-Franger 2018; Pietrzak-Franger and Holmes 2014).

While, in contrast to traditional genres, online environments offer less 'authorial' control when it comes to embedding and remixing of content, they have a variety of representational modes at their disposal. Written language can be combined with any form of illustration, voice and video recordings; it can be variously laid out and structured. These different modes of expression carry with themselves different possibilities. The particular affordances, primary purposes and demographic appeal of online platforms clearly influence the representational modes and have the potential to offer a diversity of illness portrayals. Long COVID has spurred a plethora of online representations, many of which are bottom-up articulations by patients. Whereas patients' written descriptions or selfies are probably the most prevalent forms of representation, attention to voice and video recordings (eg, in podcasts or TikTok videos) divulges further information about the illness. Shortness of breath, persistent cough and trouble speaking are but a few symptoms that may find their indexical articulation in the tone of voice, pace of utterances, pauses between them. Other representative modes reveal more about the whole experience of illness than simply about its symptoms. On a 'Map of Long COVID', that went viral on Twitter (Goldschmidt 2022) the 'Island of Isolation', as an expression of a particular experience of illness, is surrounded by 'shark-infested gaslight water'; its climate is influenced by 'migraine golf stream' and swept by 'winds of changeable symptoms'. Its typographical diversity—from 'mountains of dysautonomia' to 'fatigue swamps' and 'plateau of crashes'—only allows for 'Long Covid fantasy clinics' to be erected on this land.

This graphical rendition subsumes both the subjective corporeal experience and the struggles of a patient suffering from a poorly understood condition. In their multimodality, online environments hold and reflect the multisensorial character of illness experience. Recognising and analysing these instances, we can not only draw attention to the complexity of this experience but also help develop representational vocabularies that can counteract extant stereotyping tendencies.

Despite the representational potential of such multimodal online environments, many depictions of illness (often unintentionally) take up and perpetuate long-standing stigmatising tendencies. Beth, the owner of the @longcovidlife TikTok account, makes use of her own body, verbal and written descriptions as well as illustrations to convey what it feels like to live with the condition. When she compares her current state to driving a golf cart ('with a half-charged battery') as opposed to a car that 'has been taken from you', respective icons, stylistically resembling illustrations for children, appear at the top left corner of the video post (@longcovidlife (Beth) 2021). The icons contribute to a (generally expected) light-heartedness of the evocation. At the same time, this choice of communicative modes may unwittingly infantilise both the ill and the audience (similarly, for instance, to the infantilisation of patients with breast cancer; cf. Ehrenreich 2001). In contrast, the German-language Instagram account 'nichtgenesen', subscribes to a diametrically opposed aesthetics. With its aim to give a face to #LongCovid and related conditions (Wir geben #LongCovid, #ME/CFS und #PostVac ein Gesicht!) (@nichtgenesen n.d), it consists 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 little distinguishable backgrounds, earnestly looking into the camera. The schematic information, uniformity of representation and the black-and-white aesthetic communicate the sheer number of the affected, while, at the same time, purposefully or not, reductively defining them through their inability to work—their loss of productivity. Considering that no further information is given, the account reduces them to this one characteristic. By doing so, it stresses the representation of sufferers within the 'swooning' tradition and frames them—inadvertently so—as malingerers who do not conform to new-liberalist ideals of productivity.

Thanks to their multimodal character, online environments have a great potential to represent illness in a way that mirrors its multisensorial experience. At the same time, such environments can also perpetuate extant stigmatisation tendencies. Infantilisation and devaluation as citizens are but two examples of stigmatising strategies that have been used in popular and scientific depictions of illnesses and that, apparently and inadvertently, are taken up and perpetuated in online environments by Long COVID sufferers. Medical humanities' attention to such traditions—and their (dis)continuities—brings to light both their relentless grip on popular imagination and the urgency to intervene in those processes in order to offer nuanced (self-)depictions. One such intervention is a heightened emphasis on representational traditions and their down-sides, another, hands-on cooperations (eg, between academics and patients, eg, health influencers) to change them. Simultaneously, attention to other than written modes of expression can help expand 'the vocabulary' of illness, enrich the repertoire of signs used in this context—from symbols and icons to various types of indexes. This shift may be helpful in developing new strategies of representation that question and break with extant tendencies. Online environments can thus become sites where

the long-standing discriminatory traditions can be counteracted. Their networked character and their central role in postdigital health practices can help medical humanities spotlight patients' self-perception, identification and representation strategies both in online context as well as in their everyday behaviours.

TRANSMEDIAILITY: LINKING, SHARING, SCALING, FRAMING

Online environments indeed frame illness as a networked, interactive and intersubjective experience. Social media allow for a dynamic and ongoing polylogical exchange in this context. Commenting and re-tweeting keeps the conversation going. Exemplarily, LongCovidSOS—a group of UK Long COVID sufferers—uses Twitter, YouTube and Instagram, next to curating their own web page, to reach out to broader audiences. With the help of these platforms, individual stories of illness are linked to civic campaigns, to research articles, to news releases, to crowd sourcing possibilities and petitions. Through this linking and sharing, individual experience of illness is re-scaled and re-framed. In this process, it becomes part of larger infrastructures and frameworks of reference, such as healthcare provision (pathways), insurance possibilities or policy making.

Message in A Bottle—a film commissioned by LongCovidSOS—features a number of people unwell 3 months after the infection. In it, individuals hold pieces of paper with their personal information and the duration and types of symptoms experienced. Combined, the faces, the recurring messages, symptoms, and the voice-over narration highlight both the diversity of their experience as well as the multitude of cases, thus highlighting the necessity of action from science and medical establishment. Borrowing from the Occupy Movement aesthetics (and the 'We are the 99%' campaign), the film makes use of extant online-activist strategies, whereby stressing similar goals and positioning itself within civic-movement traditions.

Next to signalling the scale of the problem, online curation of individual stories about the Long COVID experience also highlights the importance of story-telling as an act of sharing: dialogical and polylogical acts that are crucial to knowledge construction. As Rushforth *et al* make abundantly clear:

Individually, the stories [of Long Covid-19 patients] seemed to make little sense. Collectively, they provided a rich description of the diverse manifestations of a grave new illness, a shared account of rejection by the healthcare system, and a powerful call for action to fix the broken story. Evolving from individual narrative postings to collective narrative drama, long Covid communities challenged the prevailing model of Covid-19 as a short-lived respiratory illness which invariably delivers a classic triad of symptoms; undertook and published peer-reviewed research to substantiate its diverse and protracted manifestations; and gained positions as experts by experience on guideline development groups and policy taskforces. (Rushforth *et al.* 2021, 1)

Scholars have stressed the unconvincing and unhelpful emphasis on individuality and individual choices in the face of the pandemic (Ahmed and Jackson 2021; Davies and Savulescu 2022; Lewis 2021; Schermuly, Petersen, and Anderson 2021). This emphasis on individuality has shifted attention away from systemic inequalities and larger power struggles—a feature/rhetoric effect also shared by Western outbreak narratives in the twentieth and twenty-first centuries. As Rushforth and others recognise, the multiplicity of Long COVID stories has had political valence by evidencing, popularising and thus making visible a condition which policy makers, researchers and medical practitioners—then—still needed to tackle.

These expressions of illness—be they narrative or not—spread across mediascapes. They are *transmedial* in that they are not limited to or designed for only one particular media platform (Rajewsky 2002; Wolf 2015). LongCovidSOS is a typical example of transmediality with its films hosted on the website and the YouTube channel and communicated via Twitter and Instagram. Michael Rosen's experience of COVID-19 has been articulated on Twitter and the radio, in newspapers and during reading events, along with the aforementioned book of poems and an illustrated book for children. Attending to the transmediality that characterises such contemporary postdigital health practices enables us to spotlight the various processes of negotiation that characterise both the expression, sense-making and the production of knowledge about illness. The act of sharing necessitates a proleptic translation of the experience into a form that appeals to particular audiences. Rosen's selection and ordering process in the collection of poems fills out the experiential gaps. His choice of poems for his radio and in-person reading events testifies to his awareness of the properties of spoken poetry and its emotional impact. His 'retelling' of his illness in an illustrated children's book *Sticky McStickstick: The Friend who Helped me Walk Again* (Rosen 2021b) foos on his long-term experience as children's book author. This transmedia COVID-19 microverse is but one tiny puzzle piece of a transmedia COVID-19 macroverse in which stories about the illness are told and retold across multiple platforms ad infinitum. Unlike many transmedia franchises, this environment is characterised not necessarily by a thought-out and strategic development but rather by cross-platform polyvectorality. In effect, transmedia narratives of illness, like the one developed by Rosen, are also accompanied by transmedia practices that go beyond a re-telling of story-parts. They require a closer look at who produces what narratives (or other forms of expression) and with what means; they necessitate an inquiry into how these stories circulate (or not), how they are limited, undermined, appropriated and re-appropriated and who is responsible for all this: what actants and institutions are involved in these practices and what nodes of their rhizomatic agentiality need to be spotlighted. What political potential resides in the online environments when it comes to health and illness?

Henry Jenkins highlighted the political potential of online environments in times of convergence culture. Be it 'Photoshop for democracy' or the use of social media in the Arab Spring, the reach and the spreadability of social media as grassroots instruments have been critically acknowledged (Jenkins 2006). Similarly, in the context of the pandemic, Long COVID has been hailed as the first illness that was made by patients connecting on and through social media (Callard and Perego 2021). In fact, the variety of online forums mushrooming in the course of the pandemic and the expansive digital patient activism in this area have enabled a re-scaling and re-framing of both Long COVID and the discussions around it. Alexa Stephanou, co-founder of LongCovidAustria, points out that the online presence of the group has led to the increasing acknowledgement of their perspective and, with it, partial recognition of their experiential knowledge. In the course of this process, the patients-activists have been involved in larger restructuring processes that range from the establishment of special first-contact points for patients with Long COVID (CovidAmbulanz), adjustment of rehabilitation paths and technologies, or adaptations of workspaces and modalities (Alexa Stephanou, personal communication with author, Nov. 2, 2022). Similar developments have been seen in the UK, for instance, in the interaction of patients-academics, online patient groups and the NHS. Such examples show the

centrality of online environments as entry points of postdigital health practices in a variety of processes that re-scale and re-frame illness by spotlighting its communal character and its intertwining with broader frameworks of reference, involving, but not restricted to, work and insurance infrastructures, the welfare state, policy making, and citizen rights. What is needed are studies that take these connections into consideration and thus help us trace the mundane postdigital practices of this collective exercise to better understand their political potential.

POSTDIGITAL HEALTH PRACTICES

As the examples I have used throughout the paper show, in the Western world, health practices have become *postdigital*. The pandemic has offered an opportunity to clearly see how the digital and the material world, user practices and different types of knowledge come together to form an ‘*assemblage of health*’: a combination of ‘expert sources’, ‘lived experiences and knowledge of previous infectious diseases, their affective and multi-sensory embodied responses and their engagements with other people, both in-person and online’ (Lupton 2022, 8). While intensified and accelerated by the pandemic, these tendencies have been with us since the onset of the internet era. As Oxford philosopher Luciano Floridi makes clear, we have been living ‘onlife’ lives (2014). Indeed, the pervasiveness of information and communication technologies has led to a blurring between ‘reality and virtuality’ and ‘the human, machine and nature’ as well as shifting emphasis to ‘the primacy of interactions’ (Floridi 2015). In this context, the way we practice, experience but also express our understandings of health and illness—just like illness narratives or illness accounts under any other form—can no longer be conceived of as either analogue or digital. They are all part of postdigital health practices that also medical humanities scholars need to account for.

What are, then, the characteristics of *postdigital health practices*? While the term ‘postdigital’ has been a contested one, it is worth considering its employability in the context of both everyday health practices and medical humanities. First coined to address a novel media aesthetics (Andrews 2013; Cascone 2000), it has come to be variously used by media studies, digital humanities and, among others, cultural and education scholars (Barnett 2021; Hall 2021; Jandrić and Ford 2022; Knox 2019; Selwyn and Jandrić 2020). While they differ in the focus and application of the term, many of the writings on the postdigital agree that it does not signpost a linear, teleological movement towards perfection and progress, initially associated with the digital, but rather, that it signals the end of the era of infatuation with the digital. It marks a change in sensibility, in the affective attitude towards the digital: from enthusiasm and hope to disappointment and distrust. Although I register this transformation in affective attitudes, I use postdigital as denoting three interdependent aspects of contemporary culture: (1) the mundanisation of the digital, (2) the non-binary (analogue vs digital) character of the practices that it encourages and makes possible, and (3) the complicated reshuffling of power hierarchies that it brings about.

Considered as such, the postdigital implicates digital technologies as intrinsic to and fully integrated into everyday practices (from email writing to paying for groceries to watching Netflix and using health-tracking apps). It sees the analogue and the digital as part of a seamless continuum and as simultaneously material and discursive (Barnett 2021; Hall 2021; Jandrić and Ford 2022; Knox 2019; Selwyn and Jandrić 2020). Last but not least, it considers the power relations that are thus created in

terms of dynamic, interrelated structures dependent on local contexts but also larger institutional and geopolitical infrastructures and movements. Postdigital, for me, then, encompasses both what Cramer sees as ‘postcolonial practices in a communications world taken over by a military-industrial complex made up of only a handful of global players’ (Cramer 2014) as well as the workings of those global players.

Against this background, what does it mean that health practices are postdigital? Taking extant studies into consideration, *postdigital health practices* can be said to (1) be based on interaction (with other users, with Computer-Generated-Influencers (CGIs) or avatars, and with/through apps), (2) have the capacity to influence users’ self-relations and world-relations, everyday behaviour and habits, and therefore have tangible real-life effects, (3) facilitate the establishment and growth of various communities by offering ways of peer-to-peer interaction and support, and (4) take centre stage in processes of knowledge creation and dissemination (Au and Eyal 2022; Bellander and Landqvist 2020; Bradley 2021; Callard and Perego 2021; Lindén 2021; Lupton 2014; Petersen, Schermuly, and Anderson 2020; Rueger, Dolfsma, and Aalbers 2021).

Studying postdigital health practices while taking into consideration these characteristics does not only expand the purview of medical humanities. It also answers some of the recent calls made by the representatives of the ‘second wave’. It helps spotlight the complex entanglements that characterise our everyday health practices, identify, trace, and provide larger frameworks of reference that may allow us to make sense of these entanglements, and embrace various modes of experience and strategies of its articulation that both augment and go beyond the medical humanities’ preoccupation with narrative (Viney, Callard, and Woods 2015; Woods 2011, Whitehead and Woods 2016b, Fitzgerald, D., and Bolaki 2016, Fitzgerald and Callard 2016, Giaxoglou 2022, Gonzalez-Polledo and Tarr 2016, Pietrzak-Franger 2017). In effect, shifting attention to postdigital health practices as an object of study entails acknowledging and counteracting one of the blind spots of medical humanities, which is its continuing devotion to the long-standing hierarchy of arts. Although often unadmittedly so, medical humanities scholars’ preference is for literature (with genres ranging from poetry, novel, memoir, life-writing, and, increasingly, pathoGraphics), while theatre, visual arts (paintings, sculpture and installations), dance, and music form another set of media of interest; film and television appear to constitute a third group under consideration. Some notable exceptions notwithstanding (eg, Bolaki 2016), the media and arts under consideration are looked at in separation and, mostly, outside their reception contexts or, alternatively, within the therapeutic contexts of their historical and contemporary application.

The effect of this approach is twofold. On the one hand, there is a strict privileging of traditional artistic forms and media that goes hand in hand with a disregard of other forms of expression, their connectivity and spread that have been enabled by digital environments. On the other hand, and precisely because of this narrow focus, we can observe a continuing emphasis on particular types of (fictional or factual) experience: experience that can be told or shown by actants who have managed to establish themselves on the market. As a result, a vast number of articulations of health and illness experience, along with a plethora of expressive means used in this context, remain under the radar of medical humanities scholars. If we want to stay up to date when it comes to the changing forms of expression, the transforming channels of articulation and access, we need to consider in our critical practice digital environments and the postdigital

health practices that they foster. While there are multiple ways of approaching this field, I have concentrated here on the aspect of knowledge production and drawn attention to certain affordances characteristic of digital platforms that need to be taken into consideration in this context. Using examples of COVID-19 and Long COVID, I have offered a novel tripartite model from which to study postdigital health practices, with particular attention given to the accounts of experiential knowledge.

CHALLENGES AND OPPORTUNITIES

Irrespective of its manifold blessings, the digital is a hostile environment in which to do medical humanities. Its vastness and transformative speed, various types of gatekeeping, platform-specific censorship, the digital divide, cyberbullying or the algorithmic selectivity make its systematic analysis a difficult feat. Even more so if we consider long-standing disciplinary traditions, values and hierarchies of art forms, the primacy of narrative and literature writ large. While the necessity to adjust (medical) humanities methodologies and theoretical models to embrace these new sites and practices has been recognised, more systematic work is necessary in this context.

Undoubtedly, interdisciplinary, if not transdisciplinary, models are necessary to grasp the characteristics and effects of post-digital health practices. As mentioned above, interdisciplinary alliances have been called for to consider the historical and contemporary complexity of health and illness and to rescale these and link them to larger frameworks of reference. In this way, the individual experience of illness could be linked to larger structures of inequality and discrimination. Digital humanities, with their computational tools, have been named a natural ally in this context. Indeed, systematic studies of interactions on social media platforms, for instance, can well be supported by digital humanities' methods, especially since the vastness of data, its time-consuming collection and preparation are hardly possible with traditional methods of literary, cultural or media studies. This said, even digital humanities instruments have their limitations. So far, for instance, no tool has been developed to allow for an automatic, simultaneous coding of visual and written information (those tools which have been programmed to analyse the visual, ignore the written elements so that, eg, posts can be computationally analysed either for their written or visual content, but not for both). Neither is it reasonable to expect that the transmedia networks or multimodal elements I have outlined above can easily be fed into and analysed with such technologies.

Irrespective of these difficulties, it is essential that we attend to, analyse and interpret postdigital health practices and their impact on our everyday lives: build interdisciplinary hubs, ask unorthodox questions, be open to new methods. One of the starting points in this analysis could be the use of the model I propose here. Through the attention to serialisation, multimodality, and transmediality as the prime strategies of articulation and representation of illness and illness experience in online environments, we could gain more insight into the plurality of modes in which (experiential) knowledge is communicated, and attend to the collective (digital and analogue) practices of illness articulation. Such an entry point also opens new pathways for a rethinking of the politics of illness in the digitalised world.

Twitter Monika Pietrzak-Franger @franger_monika

Acknowledgements The author thanks the group working on postdigital health practices (Vienna and Hamburg) for their comments, Carina Hilmar for helping with the compilation of the references and Alina Lange for her feedback on the paper.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data sharing is not applicable as no data sets were generated and/or analysed for this study.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

ORCID iD

Monika Pietrzak-Franger <http://orcid.org/0000-0002-9431-5999>

NOTE

1. Reading in instalments also means reading in an idiosyncratic order, dependent on algorithms, people whom we follow, online routes and detours we take.

BIBLIOGRAPHY

- @longcovidlife (Beth). 2021. "What's It Like to Have Long COVID." Tiktok. Available from: [tiktok.com/@longcovidlife/video/7044247609422187782](https://www.tiktok.com/@longcovidlife/video/7044247609422187782). Accessed Nov 2022.
- @nichtgenesen. n.d. "Wir Geben #LongCovid, #ME/CFS Und #PostVac Ein Gesicht!" Instagram. Available from: [instagram.com/nichtgenesen/?hl=de](https://www.instagram.com/nichtgenesen/?hl=de). Accessed 10 Nov 2022.
- Ahmed, A., and J. Jackson. 2021. *Race, Risk, and Personal Responsibility in the Response to COVID-19*, 121, 47–70. CLR Forum. www.columbialawreview.org/content/race-risk-and-personal-responsibility-in-the-response-to-covid-19/.
- Andrews, I. 2013. "Post-Digital Aesthetics and the Return to Modernism." Available from: www.ian-andrews.org/texts/postdig.html. Accessed 11 Nov 2022.
- Atkinson, S., H. Bradby, M. Gadebusch Bondio, A. Hallberg, J. Macnaughton, and Y. Söderfeldt. 2021. "Seeing the Value of Experiential Knowledge through COVID-19." *History and Philosophy of the Life Sciences* 43 (3): 85.
- Au, L., and G. Eyal. 2022. "Whose Advice Is Credible? Claiming Lay Expertise in a Covid-19 Online Community." *Qualitative Sociology* 45 (1): 31–61.
- Bamberg, M., C. Demuth, and M. Watzlawick. 2021. "A Narrative Practice Approach to Identities: Small Stories and Positioning Analysis in Digital Contexts." In *The Cambridge Handbook of Identity*, edited by Michael Bamberg, Carolin Demuth, and Meike Watzlawick, 241–361. Cambridge: Cambridge University Press.
- Barnett, R. 2021. "Postdigital Humans: Transitions, Transformations & Transcendence." Lecture. Available from: <https://www.ronaldbarnett.co.uk/postdigital.pdf>. Accessed 03 Nov 2022.
- Beer, D. 2016. *Metric Power*. Basingstoke: Palgrave Macmillan.
- Bellander, T., and M. Landqvist. 2020. "Becoming the Expert Constructing Health Knowledge in Epistemic Communities Online." *Information, Communication & Society* 23 (4): 507–22.
- Blume, S. 2017. "In Search of Experiential Knowledge." *Innovation* 30 (1): 91–103.
- Bolaki, S. 2016. *Illness as Many Narratives: Arts, Medicine and Culture*. Edinburgh: Edinburgh University Press.
- Borkman, T. 1976. "Experiential Knowledge: A New Concept for the Analysis of Self-Help Groups." *Social Service Review* 50 (3): 445–56.
- Bradley, B. 2021. "From Biosociality to Biosolidarity: The Looping Effects of Finding and Forming Social Networks for Body-Focused Repetitive Behaviours." *Anthropology & Medicine* 28 (4): 543–57.
- Callard, F., and E. Perego. 2021. "How and Why Patients Made Long Covid." *Social Science & Medicine* 268: 113426.
- Cascone, K. 2000. "The Aesthetics of Failure: 'Post-Digital' Tendencies in Contemporary Computer Music." *Computer Music Journal* 24 (4): 12–18.
- Cramer, F. 2014. "What Is 'Post-Digital'?" *A Peer-Reviewed Journal About* 3 (1): 10–24.
- Davies, B., and J. Savulescu. 2022. "Institutional Responsibility Is Prior to Personal Responsibility in a Pandemic." *The Journal of Value Inquiry*: 1–20.
- Ehrenreich, B. 2001. "Welcome to Cancerland" 45–53. Harper's Magazine. <https://pinkribbonblues.org/wp-content/uploads/2010/08/Ehrenreich-2001-WelcomeToCancerland-Harpers.pdf>.
- Epstein, S. 1995. "The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials." *Science, Technology & Human Values* 20 (4): 408–37.

- Fitzgerald, D., and F. Callard. 2016. "Entangling the Medical Humanities." In *The Edinburgh Companion to the Critical Medical Humanities*, edited by Anne Whitehead and Angela Woods, 35–49. Edinburgh: Edinburgh University Press.
- Florida, L. 2015. *The Onlife Manifesto. Being Human in a Hyperconnected Era*. Cham: Springer.
- Fung, I. C.-H., E. B. Blankenship, J. O. Ahweweyu, L. K. Cooper, C. H. Duke, S. L. Carswell, A. M. Jackson, et al. 2020. "Public Health Implications of Image-Based Social Media: A Systematic Review of Instagram, Pinterest, Tumblr, and Flickr." *The Permanente Journal* 24: 18.307.
- Gallistl, V., A. Seifert, and F. Kolland. 2021. "COVID-19 as a 'Digital Push?' Research Experiences From Long-Term Care and Recommendations for the Post-Pandemic Era." *Frontiers in Public Health* 9: 660064.
- Ghebreyesus, T. A. 2020. "Munich Security Conference." Munich WHO. www.who.int/director-general/speeches/detail/munich-security-conference.
- Giaxoglou, K. 2022. "Mobilizing Stories of Illness in Digital Contexts: A Critical Approach to Narrative, Voice, and Visibility." *Poetics Today* 43 (2): 287–308.
- Goldschmidt, C. 2022. "Just Popping on Here to Lend a Little Lightheartedness." @christinegoldschmidt_1. Instagram. Available from: <https://www.instagram.com/p/Cj8oHGLjTQ/?igshid=YmMyMTA2M2Y=>. Accessed 20 Oct 2022.
- Gonzalez-Polledo, E., and J. Tarr. 2016. "The Thing about Pain: The Remaking of Illness Narratives in Chronic Pain Expressions on Social Media." *New Media & Society* 18 (8): 1455–72.
- Greenhalgh, T. 1999. "Narrative Based Medicine in an Evidence Based World." *British Medical Journal* 318 (7179): 323–25.
- Hall, G. 2021. "Postdigital Politics: Or, How to Be an Anti-Bourgeois Theorist." In *Aesthetics of the Commons*, edited by Cornelia Sollfrank, Shuhsa Niederberger, and Felix Stalder, 153–77. Zurich, Berlin: Diaphanes.
- Hardey, M. 1999. "Doctor in the House: The Internet as a Source of Lay Health Knowledge and the Challenge to Expertise." *Sociology of Health & Illness* 21 (6): 820–35.
- Hastings, G. 2020. "COVID-19: Our Last Teachable Moment." *Emerald Open Research* 2: 20.
- Jandrić, P., and D. R. Ford. 2022. *Postdigital Ecopedagogies: Genealogies, Contradictions, and Possible Futures*. Cham: Springer.
- Jenkins, H. 2006. *Convergence Culture: Where Old and New Media Collide*. New York: NYU Press.
- Johnstone, F. 2018. "Manifesto for a Visual Medical Humanities." Medical humanities blog, *British Medical Journal*. <https://blogs.bmj.com/medical-humanities/2018/07/31/manifesto-for-a-visual-medical-humanities/>.
- Jones, M., P. Jallinoja, and I. Pietilä. 2021. "Representing the 'Voice' of Patients: How Third Sector Organisations Conceptualise and Communicate Experiential Knowledge in Health Service Development." *VOLUNTAS* 32 (3): 561–72.
- Keidl, P. D., L. Melamed, V. Hediger, and N. Somaini, eds. 2020. *Pandemic Media: Preliminary Notes Towards an Inventory*. Lüneburg: Meson Press.
- Knox, J. 2019. "What Does the 'Postdigital' Mean for Education? Three Critical Perspectives on the Digital, with Implications for Educational Research and Practice." *Postdigital Science and Education* 1 (2): 357–70.
- Kress, G. 2010. *Multimodality: A Social Semiotic Approach to Contemporary Communication*. New York: Routledge.
- Kress, G., and T. van Leeuwen. 1996. *Reading Images: The Grammar of Visual Design*. London: Routledge.
- Lai, J., and N. O. Widmar. 2021. "Revisiting the Digital Divide in the COVID-19 Era." *Applied Economic Perspectives and Policy* 43 (1): 458–64.
- Lewis, B. 2021. "Planetary Health Humanities-Responding to COVID Times." *The Journal of Medical Humanities* 42 (1): 3–16.
- Lindén, L. 2021. "Moving Evidence: Patients' Groups, Biomedical Research, and Affects." *Science, Technology, & Human Values* 46 (4): 815–38.
- Lupton, D. 2014. "The Commodification of Patient Opinion: The Digital Patient Experience Economy in the Age of Big Data." *Sociology of Health & Illness* 36 (6): 856–69.
- Lupton, D. 2016. *The Quantified Self*. Cambridge, Malden: Polity.
- Lupton, D. 2018. *Digital Health. Critical and Cross-Disciplinary Perspectives*. London: Routledge.
- Lupton, D. 2019. "Toward a More-Than-Human Analysis of Digital Health: Inspirations From Feminist New Materialism." *Qualitative Health Research* 29 (14): 1998–2009.
- Lupton, D. 2022. *Covid Societies: Theorising the Coronavirus Crisis*. London: Routledge.
- Mazanderani, F., L. Locock, and J. Powell. 2012. "Being Differently the Same: The Mediation of Identity Tensions in the Sharing of Illness Experiences." *Social Science & Medicine* (1982) 74 (4): 546–53.
- Neff, G., and D. Nafus. 2016. *Self-Tracking*. Cambridge, MA: MIT.
- Osther, K. 2020. Edited by Inside Higher. "Humanities as Essential Services." <https://www.insidehighered.com/views/2020/05/21/how-humanities-can-be-part-front-line-response-pandemic-opinion>.
- Osther, K. 2019. "Digital Health Humanities." In *Research Methods in Health Humanities*, edited by Craig M. Klugman and Erin Gentry Lamb. Oxford: Oxford University Press.
- Petersen, A., A. Schermuly, and A. Anderson. 2020. "Feeling Less Alone Online: Patients' Ambivalent Engagements with Digital Media." *Sociology of Health & Illness* 42 (6): 1441–55.
- Pietrzak-Franger, M. 2017. *Syphilis in Victorian Literature and Culture. Medicine, Knowledge and the Spectacle of Victorian Invisibility*. Houndmills, Basingstoke, NY: Palgrave Macmillan.
- Pietrzak-Franger, M. 2018. "Medical Mappings of Syphilis in the Late Nineteenth Century." In *Syphilis and Subjectivity: From the Victorians to the Present*, edited by Kari M. Nixon and Lorenzo Servitje, 15–37. Houndmills: Palgrave Macmillan.
- Pietrzak-Franger, M. 2021a. "A 'Visiomedic': COVID-19, Contagion Media, and the British Press." *Anglistik* 32 (3): 183–203.
- Pietrzak-Franger, M. 2021b. "Reading Victorian Skin: Perspectives in (English) Literary/Cultural Studies and Medical Humanities." In *Skin, Silk, and Show*, edited by Sibylle Baumbach and Ulla Ratheiser, 97–115. Cham: Palgrave Macmillan.
- Pietrzak-Franger, M. M., and M. S. Holmes. 2014. "Disease, Communication, and the Ethics of (in) Visibility." *Journal of Bioethical Inquiry* 11 (4): 441–44.
- Prainsack, B. 2022. "The Advent of Automated Medicine?: The Values and Meanings of Precision." In *Can Precision Medicine Be Personal; Can Personalised Medicine Be Precise?*, edited by Yechiel Michael Barilan, Margherita Brusa, and Aaron Ciechanover, 203–16. Oxford: Oxford University Press.
- Rabeharisoa, V., T. Moreira, and M. Akrich. 2014. "Evidence-Based Activism: Patients', Users' and Activists' Groups in Knowledge Society." *BioSocieties* 9 (2): 111–28.
- Rajewsky, I. 2002. *Intermedialität*. Stuttgart: A. Francke UTB.
- Rosen, M. 2020. "Day 12 The Year's Seasons Roll by in a Night: Sweats, Freezes, Sweats, Freezes. Wondered Whose Mouth I Had: I Didn't Remember It as Made of Sandpaper. Water Is as Good as Ever." @MichaelRosenYes. Twitter. Available from: twitter.com/michaelroseny/status/1243490288154431488. Accessed 11 Nov 2022.
- Rosen, M. 2020b. "God Yes. Tongue Looks like an Andouillette and Apart from a Grape, Lemon Tea, and Orange Everything Gets Turned into Metallic Sick. First Day Not Though. You've Had Breathing Probs?" @MichaelRosenYes. Twitter. Available from: twitter.com/MichaelRosenYes/status/1241384027829010442. Accessed 11 Nov 2022.
- Rosen, M. 2020c. "Physio, Dearest Emz?! They're Teaching Me How to Walk. And My Legs Don't Want to." @MichaelRosenYes. Twitter. Available from: twitter.com/michaelroseny/status/1271195668355350531. Accessed 11 Nov 2022.
- Rosen, M. 2021a. *Many Different Kinds of Love: A Story of Life, Death and the NHS*. London: Ebury Press.
- Rosen, M. 2021b. *Sticky McStickstick: The Friend Who Helped Me Walk Again. Illustr. Tony Ross*. Somerville, MA: Candlewick Press.
- Rosen, M. 2021b. "I Am Not Who I Was: Michael Rosen on Surviving Covid – Extract." The Guardian. Available from: <https://www.theguardian.com/books/2021/mar/13/i-am-not-who-i-was-michael-rosen-on-surviving-covid-extract>. Accessed 11 Nov 2022.
- Roth, P. H., and M. Gadebusch-Bondio. 2022. "The Contested Meaning of 'Long COVID' - Patients, Doctors, and the Politics of Subjective Evidence." *Social Science & Medicine* (1982) 292: 114619.
- Ruckenstein, M., and M. Pantzar. 2015. "Datafied Life." *Techné* 19 (2): 191–210.
- Rueger, J., W. Dolfsma, and R. Aalbers. 2021. "Perception of Peer Advice in Online Health Communities: Access to Lay Expertise." *Social Science & Medicine* 277: 113117.
- Rushforth, A., E. Ladds, S. Wieringa, S. Taylor, L. Husain, and T. Greenhalgh. 2021. "Long Covid – The Illness Narratives." *Social Science & Medicine* 286: 114326.
- Schermuly, A. C., A. Petersen, and A. Anderson. 2021. "'I'm Not an Activist!': Digital Self-Advocacy in Online Patient Communities." *Critical Public Health* 31 (2): 204–13.
- Selwyn, N., and P. Jandrić. 2020. "Postdigital Living in the Age of Covid-19: Unsettling What We See as Possible." *Postdigital Science and Education* 2 (3): 989–1005.
- Viney, W., F. Callard, and A. Woods. 2015. "Critical Medical Humanities: Embracing Entanglement, Taking Risks." *Medical Humanities* 41 (1): 2–7.
- Wasson, S. 2018. "Before Narrative: Episodic Reading and Representations of Chronic Pain." *Medical Humanities* 44 (2): 106–12.
- Whitehead, A., and A. Woods. 2016. "Introduction." In *The Edinburgh Companion to the Critical Medical Humanities*, edited by Anne Whitehead and Angela Woods, 1–31. Edinburgh: Edinburgh University Press.
- Whitehead, A., and A. Woods. 2016b. *The Edinburgh Companion to the Critical Medical Humanities*. Edinburgh: Edinburgh University Press.
- Whitson, J. 2014. "Foucault's Fitbit: Governance and Gamification." In *The Gameful World*, edited by Steffen Walz and Sebastian Deterding, 339–58. Boston, MA: MIT Press.
- Whitson, J. R. 2013. "Gaming the Quantified Self." *Surveillance & Society* 11 (1/2): 163–76.
- Whooley, O., and K. K. Barker. 2021. "Uncertain and under Quarantine: Toward a Sociology of Medical Ignorance." *Journal of Health and Social Behavior* 62 (3): 271–85.
- Wolf, W. 2015. "Literature and Music: Theory." In *Handbook of Intermediality: Literature – Image – Sound – Music*, edited by Gabriele Rippl, 459–74. Berlin: De Gruyter.
- Woods, A. 2011. "The Limits of Narrative: Provocations for the Medical Humanities." *Medical Humanities* 37 (2): 73–78.
- Woolf, V. 2012. [1926]. *On Being II*. Ashfield, Massachusetts: Paris Press.