

ILLNESS, NARRATED

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Stay¹ healthy, stay safe. The new closing remark to many emails, phone calls and conversations is telling of a radical change in the perception of illness that took place during 2020/2021. Living and working through the COVID-19 pandemic have given a new urgency to the commonplace phrase, adding weight to an offhand farewell. This new signature does more than wish the other well; it also acknowledges a communal present that affects everyone, from the individual to national societies and global relations. Health, and its precarious situation, has found its way into people's homes, where incidences, virologists' opinions and mutant forms are discussed over dinner. 'Stay healthy' indicates our hopes for the other not to be infected; 'stay safe' marks our hopes that they keep viral threats at bay. The realities of constantly being on a spectrum of health and illness has intruded on daily life and gone beyond conversations with medical professionals or intimates to become 'the talk,' a communal and shared present.

Such a present has given a more acute relevance to this guest-edited special issue, which deals with the way in which illness is mediated through narrative forms. The relation between illness and narrative is one that has been under frequent (inter)disciplinary scholarly attention, questioning the extent to which these concepts can be seen as mutually constitutive. The two concepts interact in multiple ways. Narrative forms influence the way illness is subjectively and collectively experienced; yet this relation can also be seen to work the other way around, where illness affects the narrative form used to portray these experiences. As this interplay foreshadows, the relation remains a complex one, where illness and narrative continuously interact to produce different relationships between the experience of illness and narrative and cultural form.

In their intervention into mainstream ways of working with narrative when thinking of illness, Anne Whitehead and Angela Woods offer a critical view on the forms of power that are at play in an experience of illness. Their contribution to the debate on the role of narrative in the medical humanities lies not only in widening the discussion on conditions for the narration of patients' illness experiences, but also in how this is dealt with in scholarly attention. They maintain that the humanities' engagement with medicine has limited itself to the interaction between patient and medical practice. The limitation of this focus, described by them as "the humanities [...] looking at medicine looking at the patient,"² is that the medical humanities has failed to address the various

other factors already involved in this encounter. Different “cultural, historical and institutional setting[s]”³ or matters of intersectional discrimination, including race, class, gender, sex and able-bodiedness, are partly constituted by medical knowledge while they also shape the medical encounter in different ways.

This issue emerges in the wake of Whitehead and Woods’s critique, and offers an explicitly interdisciplinary engagement with the concepts of narrative and illness. Following Des Fitzgerald and Felicity Callard, we hope not only to have staged a “polite exchange between a range of disciplines” but to invite disciplines to also engage with each other.⁴ Such an engagement is elegantly demonstrated in the essay by Monica Greco and Paul Stenner. Moving between medicine, sociology, philosophy and literature, their essay stays with the complicated relation between stories and self-understanding and argues against the elevation of narrative to an ontological norm. As they critically focus on the role of stories in understanding lived experience, they start from Dostoevsky’s *Notes from the Underground*, in which living through stories is described as a modern illness. Following Dostoevsky’s trepidation that a process of textualization will result in a negative relationship to human embodiment, they trace what they call a “prophecy of de-realization” to the narrative turn in psychology, where narrative, discourse and stories are understood as constitutive factors of identity.

In line with the focus of their essay, the various contributions collected in this issue move beyond the discussion on illness and narrative as a cultural mode of self-expression and address the multiple ways in which narrative matters for illness. The *Essay* by Jon Arrizabalaga shows that illness is a product of social meaning and knowledge-making processes in which various players name, frame and claim interpretations over a disease at a certain time. Focusing on what is nowadays known as venereal syphilis, Arrizabalaga traces the different names and respective contextualizations of the illness from the 15th century to the present day, arguing for a view of infectious disease as a dynamic interaction, rather than a biological constant. In this sense, illness is a social variable that is understood through connected, often competing narratives. Key to understanding illnesses, and their intimate connections to central aspects of social life, is understanding those narratives and how and why they were created by different groups in different (historical) contexts.

This issue brings together various disciplines, like history, film and media studies and critical cultural analysis. Across these, it is the wide range of objects of study which

stands out. Thinking of narrative beyond literary representation, the scope of the material that is discussed shows the productiveness of engaging with illness and narrative through for instance film, archival sources, oral tradition or textile art. Showing how illness experience is communicated in the respective material, these types of engagement with narrative beyond medial and textual borders illustrates how stories of illness are formed, shaped and transferred in this respective material. Overall, these analyses show how these different stories come to be lived and how they become part of our embodied everyday life.

In this everyday, online spaces have become indispensable and contribute to the diversification of illness narratives. The opening up of the formerly closed space of the medical encounter to online platforms is addressed in the contributions by Shannon Sandford and Astrid Joutseno, both working with the medium-specific affordances of sharing an illness narrative online. The *Article* by Sandford reflects on the digital turn in autobiographical writing and illness narratives more generally. Departing from Allie Brosh's webcomic *Hyperbole and a Half*, Sandford makes a compelling argument for graphic medicine as a form of literary counterculture that is able to address fractured stories and fractured selves through word and image, challenging dominant medical discourses. Analyzing blogs and memoirs written by terminally ill mothers, Joutseno argues for a reading of these blogs as powerful counter-narratives. Following the blogs over different stages of their authors' illnesses, she observes and identifies how the described mothering strategies change as death draws closer. Eventually, she shows how blogging in the face of death can resist norms of illness and dying as well as norms of ideal motherhood.

In line with this identification of counter-narratives, the *Article* by Janin Tscheschel approaches illness narratives in documentaries, proposing a new perspective on conventional approaches in documentary studies. Departing from *Life, Animated* (2016), Tscheschel builds a case for understanding what she calls animadocs as a means of making subjective illness experience accessible to audiences. In her reading, Disney films become part of a therapeutic narrative that provide, on the one hand, a directory for the documentary's protagonist on the autism spectrum and, on the other, 'therapeutically treat' spectators in that they offer new ways of seeing and understanding the condition.

Many of the articles collected in this issue deal with the place of marginalized or minority groups vis-à-vis medical knowledge or normativity. Be it in protest against sexism in medical knowledge in Dagmar Wernitznig's contribution, or by a search for alternative ways to bridge such a knowledge gap in Emma McKenna's text, these *Articles* approach the relation between illness and narrative to voice what medicine has silenced, or what has been unspoken in dominant discourse. Wernitznig's situated analysis of women's war trauma in a rural psychiatric clinic in Austria gives voice to women's experiences of war. Often traumatic, and often silenced by way of damaging treatment or gendered psychiatric diagnoses like hysteria, Wernitznig shows how different formulations of disease have the power to marginalize people's experiences, in this case leaving the stories of women in war untold. In Emma McKenna's contribution, the failure of the medical system in relation to gender and race is connected to the discussion of endometriosis. Working with medical, cultural, digital and arts-based narratives of endometriosis, she considers her own relation to this common but little-known illness as well as the possibility of accounting for it beyond the constraints of written language. In conversation with feminist disability studies, she demonstrates her textile art as her preferred form to communicate her experience of the deeply gendered chronic illness.

One of the red threads running through these diverse contributions is one in which the body or lived experiences are not easily translated into words. In the only contribution that centers on visual elements, the *Perspective* by Kamila Iżykiewicz works with this difficulty in her speculative design project called *The Dress for the Hunchbacked Girl*. As a dialogue with her own disability, she designed a dress to tell the story for her experience of Scoliosis. Not to be worn, but to be seen by people, the dress asks questions on normativity and society's relationship with disability. Transferring her experience into a dress, it is the dress that speaks that which words cannot, simultaneously showing that a narrative form is not confined to words alone.

The difficulty of putting an illness experience into words is reflected on in the *Perspective* by Ann Wallace, who shares her journey with the newly emerged condition often referred to as long COVID. She describes her experience of navigating a stream of often confusing information of the new disease and struggles in what she describes as the 'Kafkaesque maze' of the US health system. During illness, chest pain, exhaustion and brain fog all interfered with her ability to give a narrative account. Thinking

of Arthur Frank's concept of the chaos narrative as a 'record of life,' she beautifully reflects on the fragmented feel of illness, and on the difficulty of expressing her experience in a coherent way. Birgit Däwes identifies this sense of communal insecurity during a pandemic in her readings of Edgar Allan Poe, Ling Ma and Lawrence Wright. In her *Article*, Däwes analyzes the role of the mask and the masquerade in the genre of pandemic fiction. While drawing attention to the manifold levels of entanglement between illness and narration, she specifically observes pandemic fiction as an indicator of people's anxieties, and social and political shifts.

Some of these shifts have become blatantly obvious during the COVID-19 pandemic. The preponderance of health and illness in daily conversations can be considered a significant turn in public discourse in which the fear of illness and the very experience of being ill have taken on a new role. While the virus itself may not discriminate, COVID-19 has exposed many already existing health disparities, thus demonstrating how the experience of illness cannot be separated from its cultural and political situatedness. Whether in different media such as film or online spaces, in relation to marginalized groups and silenced experiences, or beyond conventional narrative form, the 'new normal' during the pandemic has opened up new trajectories of narrating illness and of illness being narrated. With this issue, we hope to have offered a platform in which both the conceptual interchange between narrative and illness, as well as the lived, experienced, bodily effects of their mutual constitution can be discussed in close relation to each other. Making space for different perspectives and approaches means to be aware of the fact that illness itself does not adhere to disciplinary boundaries or single narrative forms. Eventually, it is an exchange that hopes to contribute to a widening of the discussion: to critically reflect on 'the talk' of illness, at present and beyond.

Stay healthy, stay safe.

The Guest Editors of "Illness, Narrated"

Endnotes

- ¹ We would like to express our gratitude to all contributors for the time and work they put into this issue, and for sharing their stories and perspectives. Special thanks goes to Max Bergmann for enabling the issue, and to Lucia Toman and the *On_Culture* Editorial Team.
- ² Anne Whitehead and Angela Woods, "Introduction," in *The Edinburgh Companion to the Critical Medical Humanities*, eds. Anne Whitehead et al. (Edinburgh: Edinburgh University Press, 2016), 1–31, here: 2.
- ³ Whitehead and Woods, "Introduction," 2.
- ⁴ Des Fitzgerald and Felicity Callard, "Entangling the Medical Humanities," in *The Edinburgh Companion to the Critical Medical Humanities*, eds. Anne Whitehead et al. (Edinburgh: Edinburgh University Press, 2016), 36–49, here: 36.