



INTRODUCTION

Illness Narratives, Networked Subjects, and Intimate Publics

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This themed section of *Catalyst* examines the material effects/affects of illness, disability, dying, and death, enduring topics across the humanities and social sciences that have become, in recent years, the focus of scholarly investigation in fields like communication studies, STS, medical anthropology, and feminist and queer science studies (Braidotti 2013, Fassin 2007, Mialet 2012, Serlin 2010). Online spaces have become notable sites of such inquiries (Arnold et al. 2017, McCosker and Darcy 2013). In much of this work, scholars track the emergence of complex, intimate publics through encounters between patients and caregivers, among networks of mourners, and through subjects who trade paradigms for “how best to live on, considering” (Berlant 2011). Drawing on media

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studies and textual analysis, other scholars examine face-to-face interactions, privately sent emails, posts on semi-public Facebook walls, and the public comment sections of personal illness blogs that participate in the production of both subjects and publics. People who are ill or dying may describe their own affective, embodied, psychological, and existential conditions over social media platforms, through illness blogs or comedy performances, in artistic creations, over GoFundMe campaigns seeking money to help with medical costs, during in-person support group meetings, or in emails sent to update established social networks (Jain 2013). Caregivers may give voice to their own experiences through similar outlets, producing and circulating knowledge about their positions as workers who, facing burnout or illness, need care themselves.

The pieces in this themed section demonstrate how these diverse sites of cultural production galvanize personal narratives, engaging with experiences of pain and loss, to create new publics (and counter-publics) or mediate new forms of networked subjectivities. Taken together and individually, these pieces consider the ways that human-technological assemblages intersect with illness narratives, and how these assemblages help us make sense of such intrusions. They show individuals, communities, and institutions grappling with the day-to-day realities of illness, disability, dying, and death, along with their more profound implications. As a reflection of the authors' experiences with illness or around illness, they illustrate the ways in which these life events disrupt and redefine the lives we imagine for ourselves. The stakes of this section feel all the more heightened by the chilling political climate taking shape across the Global North, where people who are the most vulnerable are in danger of losing their access to health care or having health care as a right of citizenship significantly abridged. In the US, with ongoing threats to the integrity of the Affordable Care Act and the protections of the Americans with Disabilities Act by the Trump Administration, we have witnessed a resurgence of activism around issues of illness and disability. This themed section makes the case that

illness, disability, dying, and death continue to be sites where networked subjects are made and intimate publics spark collective political intervention through an array of online spaces.

Illness narratives are crafted not only by those who are personally ill, but by the experiences of those around them; illness bloggers often write about the ways their friends and family are coping as they detail their own lives. The stories we tell about these experiences illustrate the challenges of making a life when living is a challenge. Social media platforms and the popularity of illness blogging, along with other illness-related online networks, make clear the undeniable impact these new social forms have on one's relationship to illness. Through these digital intimate publics, private cancer scars—whether physical or emotional—can be shared with a broader community. In their articles, Susan Jacobson and Reisa Klein each describe the long-term companionship afforded by sites like Instagram and YouTube, where individuals with breast cancer can come together, share information, or simply vent. Parsing these networked subjectivities is vital work; it helps us understand emerging modes of sociality that afford patients and caregivers the community, language, and access to resources they need, while also situating our own often individualizing experiences of illness and dying within broader social and political contexts.

Also crucial to this section is the role of what Abou Farman (2017) calls “terminality,” or what it means to live with the knowledge that one's time is limited, if in less than certain terms. We are interested in the long-term, transtemporal, and intersubjective co-mingling of the living and the dead, particularly in online spaces. To preserve an illness narrative for posterity and to share one individual's story with a broader audience can have lasting political and emotional import. Stuart Murray's and Deborah Steinberg's contribution is an important example of this kind of transtemporal collaboration. Their work examines the capacities for overlap between academic writing—which is so often portrayed as cerebral and disembodied—and illness blogging. Through experiences with terminal cancer, their work becomes more intersubjective. Illness

blogs are associated with affective and communicative labor, including care for the self and others: “[b]log tools offer their users (and authors and readers) a continually renewable capacity to produce, express, and connect with others, while also undertaking the often all-encompassing and highly intimate emotional, physical, and relational management associated with their illness” (McCosker and Darcy 2013, 1267). The production and maintenance of illness blogs is inherently collaborative and embodied.

Other pieces in this themed section examine aspects of the relationship between illness narratives and creative practice. Melanie Chilianis and Ardath Whynacht consider the ways that illness informs artistic creation, either for individual practitioners or in collaborative, group settings. Such work points to the more subversive potentialities of illness narratives, especially given concerns over the co-optation of health information as a mode of privacy invasion and surveillance. Along these lines, Kirsten Ostherr’s essay on the data-fication of personal health information considers the role of such data imaginaries in fomenting tensions between patient-driven and clinic-driven portrayals of illness, which some argue has fulfilled neoliberal promises of an ever-more-optimized self. Ostherr notes how personal narratives may be mined for valuable data by a variety of stakeholders, from advertisers to insurance companies.

Throughout the process of writing, reviewing, and editing the articles that comprise this section, we have experienced first-hand how personal illness and loss have delayed or otherwise complicated the many drafts, emails, and exchanges that constitute a scholarly dossier: the long-term temporal mapping of academic labor does not always or precisely coincide with the embodied aspects of its production. Steinberg sadly passed away during the editorial process of this section and, following her wishes, Murray continued to work on her article to ensure its inclusion herein. As a kind of praxis of this transtemporal and intersubjective co-mingling, their work includes the voices of both authors in conversation with one another as a testament to and in defiance of

terminality. Illness narratives produce intimate publics and networked subjects, but the preservation and maintenance of such narratives has its own distinct effects. To care for a dead loved one's blog is an act of continued love as well as a form of archival practice, keeping this shared experience for purposes of posterity. To that end, we have also included a PDF of Steinberg's illness blog in an attempt to share it with *Catalyst* readers and to preserve it in case it disappears from its domain name.

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