



UvA-DARE (Digital Academic Repository)

Illness online

Popular, tagged, and ranked bodies

Sánchez Querubín, N.

Publication date

2020

Document Version

Other version

License

Other

[Link to publication](#)

Citation for published version (APA):

Sánchez Querubín, N. (2020). *Illness online: Popular, tagged, and ranked bodies*. [Thesis, fully internal, Universiteit van Amsterdam].

General rights

It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations

If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: <https://uba.uva.nl/en/contact>, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

***Chapter 5 Conclusions:
Algorithmic visibility,
edited selves, and
liveness.***

Illness is the subjective experience of the person who is sick. Diseases are disorders in the functioning of a person's body. Doctors read and measure diseases with scientific equipment. Illnesses are told in the first-person. These personal accounts of illness are called 'illness stories' (Hawkins, 1999; Frank, 2013). They address suffering and hope and the radical alterations that illness introduces in a person's life. Telling stories about illness—be that through diary-keeping, public speaking, writing memoirs, or posting online—involves the ordering of experience, reflection, and the (potential) reclamation of agency.

This book has been the result of an investigation on emerging practices of illness storytelling on social media. That is to say, I investigated how people use social media to speak about their illnesses, the types of stories they tell, and what telling these stories affords them. I presented three types of social media illness stories; namely, the stories of *popular bodies* on YouTube, *tagged bodies* on Instagram, and *ranked bodies* on GoFundMe, a crowdfunding site. I saw the need to situate, theorize, and devise the means to analyze these types of stories. To meet these goals, I organized this book and my doctoral project around interconnected disciplinary, theoretical, and methodological challenges.

The disciplinary challenge I resolved in a lengthy literature review in Chapter 1. The review positioned social media illness stories, more generally, and the types I proposed, more specifically, within the health humanities. The health humanities pursue humanities-based research about health and its potential applications to healthcare. Accordingly, in the review, I described how different fields in the humanities, including literature and narrative, cultural studies, history, and media studies approach the subject of illness.

Illness stories, as I explained, have been studied extensively using literary and narrative concepts. These are the two most common approaches in health humanities research. I illustrated this point using the work of literary scholars, but also sociologists and medical anthropologists, who use narrative theory to study illness stories. These authors have explored themes, plots, and metaphors in novels, memoirs, and diaries written by people who have cancer, HIV/AIDS, and suffer from mental health issues (Biro, 2010; DeShazer, 2013).

I emphasized in this review also the contributions of sociologist Arthur Frank (2013) and literary experts Anne Hunsaker Hawkins (1999) and Anne Jurecic (2012). These authors identify types of illness narratives and master plots, which are recurring stories with a great deal of rhetorical power. Through these narrative types, Frank, Hawkins, and Jurecic exemplify how illness stories are unique to the people who tell them but, at the same time, are crafted using shared cultural resources, which can be studied. This last point about the shared characteristics of stories became relevant in my own argument, as I, too, proposed

types. Moreover, I referenced and built throughout my investigation on Frank's story types, specifically, on the restitution narrative (which are stories about cure) and the quest narrative. The quest is about patients searching for meaning beyond treatment and becoming 'wounded storytellers' and healers, that is, people who share their personal stories to help others in similar circumstances.

In the literature review, I also included other humanities approaches relevant to the study of illness—specifically anthropology, cultural studies, and the history of medicine (Lupton, 2012a; Parry, 2013). I considered it pertinent to highlight how these fields further the understanding of illnesses as culturally-specific experiences, in negotiation with ideology and changing discourses about gender and politics. Then, per the health humanities framework, which is both academic and applied, I used the work of Crawford et al. (2015) to discuss the application of concepts from the humanities in medical education and healthcare. An example of this application was the program in medical narrative offered by Columbia University. The program teaches literary competencies to medical students, so that they can become better listeners of their patient's stories.

Afterward, I focused on media studies scholarship that dealt with the subject of illness storytelling, understood broadly. I organized this section of the review around three pathways, that is, ways for thinking about the study of illness and media. The first 'pathway' pertained to the representation of patients and doctors in television and newspapers. The work of Friedman (2004), Turow (2010), and Ostherr (2013) helped me map concerns driving this area of research. These include, for example, the representation of hospital life in television dramas and their growing focus on the troubled lives of doctors. These authors also remarked on mass media's preference for the extreme aspects of illness, celebrity patients, cure-focused news stories, and the framing of cancer as an opportunity for self-discovery in films. These representations (and their preferences) matter. They become 'master plots' that shape people's expectations about how doctors and patients behave.

I followed the section on mass media with a review of electronic literature about illness. Electronic literature, according to researchers such as Rettberg (2019) and Hayles (2008), is writing that explores the capabilities of computers and networks. This writing, as I explained in that section, reworks ideas about narrating to the media-specific qualities of computers and media platforms. Attention to the materiality of media is critical for understanding electronic literature.

The intersection of illness and electronic literature is interesting and, also, understudied. Especially intriguing is the deployment of technical and narrative devices such as hypertext, non-linear storytelling, and generative design in the communication of illness. As an example, I discussed 'Queerskins' (Szilak, 2012), a hypertext novel about a young gay doctor who dies during the AIDs epidemic.

The novel is read by navigating and exploring the diary entries and photographs left behind by the main character, which are displayed on the screen in a collage-like manner. The fragmented nature of the reading conveys a sense of loss and trauma. In 'Reagan's Library' (Moulthrop, 1999), another hypertext work, the text on the screen is programmed to change as the reader progresses. This degenerative writing embodies a metaphor for Alzheimer's disease. Similarly, players of the video games 'Depression Quest' (Quin, 2016) and 'That Dragon, Cancer' (Green, 2016) are confronted with decision-making and puzzles that evoke the fatigue of depression and the labyrinthine life of caretakers.

The last 'pathway' and, thus, the final step in my literature review and last disciplinary challenge of my doctoral project, pertained to the study of online illness stories. These stories are not cancer novels published online or electronic literature written using social media. They are also not professional audio-visual pieces or journalist writing, like the examples included in the section on mass media. Instead, online illness stories are the everyday communications and storytelling activities of patients in chatrooms, emails, discussion boards, YouTube, GoFundMe, and Instagram.

To contextualize these storytelling activities, I used the concepts of platform and affordances. Platforms are the socio-technical environments where stories are told using media affordances such as posting, uploading images, tagging content, and writing captions. Users interact with illness stories, which are also social media content, by reading, sharing, liking, and following them. Platforms, in turn, organize stories and user interactions into timelines (which are ranked lists of social media content) and networks of related content. These outputs invite narrativizing. Not coincidentally, researchers see social media profiles and timeline as forms of biography (Fallon, 2014) and networks, as composed of fragments and stories (Tembeck, 2016).

Moreover, I framed online illness storytelling by patients as the work of "networked selves" (Papacharissi, 2018; 2019) and micro-celebrities (Senft, 2008). Networked selves are people who use technology to tell stories about their selves (and their illnesses) and negotiate their place in the world. Micro-celebrity is an expression of the networked self. It involves curating personal information to draw attention and managing audiences. In this section, I reviewed the work of authors like Orgad (2005), McCosker (2013), and Stage (2017), who brought illness theory together with ideas of online self-representation, affordances, and networked selves. For example, Stage studied blogging and proposed the concept of the entrepreneurial pathography, on which I built on Chapter 2. Entrepreneurial pathographies are the illness stories of cancer bloggers who raise awareness and funds for charities, and who thus use their stories to generate value.

Overall, I learned from authors like Papacharissi, Stage, McCosker, and Orgad that media affordances and the methods embedded in platforms, that is, how platforms organize activity and create data, shape illness storytelling in significant ways. The study of social media illness stories required sensitivity to affordances, platforms, and online vernacular practices and to how these elements come alive in people's hands.

The concrete outputs of my theorization —my answer to second challenge of my doctoral project — was a typology of social media illness stories. More pointedly, I proposed the stories of *popular bodies* on YouTube, *tagged bodies* on Instagram, and *ranked bodies* on gofundme.com. Each type of story addressed a socio-technical condition and medium-method essential to how illness is told online.

I chose to employ digital methods —the answer to the third challenge of my doctoral project— to study the stories of popular, tagged, and ranked bodies. In the methodological section of this book (also, in Chapter 1), I defined and positioned digital methods with respect to other frameworks for conducting research with the Internet. Digital methods (Rogers, 2019), I explained, are different from digitized methods that adapt offline research techniques to the study of online data. Digital methods are also distinct from the digital humanities, where researchers use software that automates aspects of literary analysis and apply them to digitized data. Digital methods, by contrast, are methods native to online media applied to online data.

Digital methods techniques are developed by *repurposing* the digital elements found in platforms (e.g., tags) and the methods used by the platforms themselves to handle these elements (e.g., networked-making and recommendation). The term 'repurposing' is important. Many of the digital elements and methods of social media platforms are designed to support marketing research and the optimization of popularity. In digital methods, one repurposes them outside of their intended use, namely, for research into social issues and illness.

For the purpose of this book, digital methods helped me engage directly with the methods of the platforms that I was concerned with, YouTube's popularity metrics, repurposing Instagram's tagging, and GoFundMe's ranking. These methods of the medium became key aspect of my typology and the case studies I used to develop the concepts further. In the next section, I revisit each of these case study chapters by reflecting on their main contributions, specifically, in relation to issues of agency and visibility.

Case studies and lessons about illness online

In Chapter 2, *Popular Bodies: Vlogging at the End of Life*, I studied the stories of *popular bodies*. These are the stories of patients who vlog on YouTube and practice micro-celebrity. Popularity is for them both a status (to be well-known and liked) and a product of the methods embedded in YouTube. In platform terms, to be ‘popular’ is the result of accumulating views and comments, which, in turn, lead to vloggers ranking high on YouTube's search engine. In the chapter, I explored the particularities of being such a popular patient and the relationship they have with their audiences.

The case studies were the vlogs of Sophia Gall, an Australian teenager, and Daniel Toms, a British man in his mid-thirties. Sophia and Daniel vlogged about living with cancer and their transitions into the end of life using conventions from lifestyle vlogs. As lifestyle vloggers do, Sophia and Daniel documented their lives, interacted with viewers, collaborated with other content creators, and sold merchandise. They posted videos frequently and urged viewers to follow, subscribe, and comment; illness was not told but updated. They both amassed millions of views.

I performed what I called a ‘filtered reading’ of the vlogs. In the first reading, I analyzed the vlogs chronologically and identified themes. In the second reading, I explored the vlogs through their most engaging video, which in both cases, was the video in which the vloggers announced that their illnesses had become incurable.

Vlogging and online popularity, the analysis revealed, was meaningful for Sophia, who no longer attended school, and for Daniel, who was unable to work. Much of their time was, indeed, spent in hospitals and at home. Making their lives visible online was something they could do from these places, at least for a time. They both expressed their appreciation for vlogging and their viewers and celebrated milestones such as reaching 100 thousand subscribers. Recovering a sense of agency and ‘voice,’ as I came to also understand through my analysis, was intertwined with Sophia’s and Daniel’s ability to tell stories that went beyond treatments and disease and their ability to practice micro-celebrity. The latter is an edited and calculated performance of the networked self.

Sophia alternated between talking about illness and her love for fashion. Daniel raised awareness about having a rare form of cancer and envisioned popularity as a vehicle to gather information about this condition. When it came to his medical exams, he invited viewers to come ‘along for the ride’ and charmed them with raw honesty and humor. By choosing which aspects of their illnesses to show, and by alternating between speaking about life as patients and their other interests, they managed to, as I came to interpret it, create an opportunity to be

more than their diseases. After Sophia and Daniel announced that they were dying, as expected, their health and energy and vlogging started to change and decrease. In Sophia's case, there were prolonged periods of silence. These changes led to some viewers questioning the value and sincerity of the vlogging activity. Is vlogging a productive activity for terminal patients? Do the viewers get to see the 'whole story'?

Sophia and Daniel addressed these attacks on their authenticity by remarking on the importance of curating, editing, and of not telling the whole story. Sophia explained, for example, that as her health declined, she only wore makeup for her videos. In these videos, she was not just Sophia, the patient, but also Sophia, the beauty vlogger. Daniel also spoke candidly about choosing to vlog during the peak of his medicine and clarified that there were aspects from his life that he did not make public. Moreover, the pace of online publishing and updating is challenging for a person who is seriously ill and dying. While this statement should be, perhaps, self-evident, the comments sent to Sophia and Daniel indicate otherwise. These accusatory comments appear to overlook the work-intensive and edited nature of social media, as well as the progression of illness. In all, lifestyle cancer vlogging expanded the possibilities of what Sophia and Daniel, as sick people, could aspire to do. However, online popularity and visibility also led to them being policed and critiqued by audiences – something that, on YouTube, illness storytellers need to manage.

In the book *When Breath Becomes Air*, which I referenced in Chapter 1, neurosurgeon Paul Kalanithi is diagnosed with terminal brain cancer. He dies before finishing his memoir. His wife, Lucy Kalanithi, took on the job of finishing the book. We, the readers, learn about it only in the epilogue. Kalanithi's struggles with his writing remained a private matter. Daniel and Sophia's struggles did not. Studies have also been written about ill celebrities and the treatment of them by the news media. However, to deal with the public death of sick micro-celebrities emerges a new societal matter.

In Chapter 3, *Tagged Bodies and Wounded Healers*, I wrote about the stories of tagged bodies on Instagram. These are stories about people who suffer from disenfranchised conditions and use Instagram to tell (and tag) their stories. In other words, on Instagram, breaking the silence involves making oneself searchable and networked. As case study, I explored how the platform has become a space in which women discuss stillbirth and fight the stigma that surrounds it.

Instagram posts typically include images, captions, and hashtags. An image could be of a sonogram, posted to Instagram, on the anniversary of a stillbirth. The caption would recall the event and the resulting grief and include hashtags such as 'stillbirth,' 'still loved,' 'angel mom,' and 'angel baby.' Clicking on any of these hashtags, redirects users to related content about stillbirth and to a community of

bereaved parents. From the outset, I was intrigued by these hashtags practices and set to repurpose them in my analysis. I saw them a specialized language and data about motherhood and grief. What was tagging affording bereaved women?

To study this activity I created a collection of posts on the topic of stillbirth and captured their associated metadata, including captions and hashtags. Then, I used software to visualize the collection as a co-hashtag network. In this network nodes are hashtags and edges appear to indicate that people use certain hashtags together in posts. The topography of the resulting network guided my close reading of these posts and enabled me to explore the role that hashtags play in the stillbirth online community. I theorized these practices (and network) using Michele Zappavigna's (2018) definition of hashtags as 'searchable talk.' With this term, Zappavigna frames hashtags as both metadata that supports the visibility of content and grouping and as semiotic devices that make meaning.

The analysis illustrated that, on Instagram, hashtags help sustain rituals that make grief "ambient." The latter is Zappavigna's term for describing a mode of association (of being together) based not on conversation but on the awareness of others. Adding tags also added extra-contextual information about loss and helped tell stories. For example, the selfie of a pregnant woman that includes the hashtag 'stillbirth,' tells a story about loss. Hashtags are also used to connect bereaved parents with makers and charities, thus supporting an online consumer culture around pregnancy loss.

Ultimately, stillbirth, my work illustrated, became visible not only by 'telling the story', but also by having the story tagged, treated as data, placed into networks, and made ambient. Tagging helped these social media users resist the testimonial injustice that surrounds the experience of stillbirth. I saw this storytelling and tagging activities as media-specific manifestations of Frank's concept of 'wounded healing', that is, storytelling by which people who suffer regain agency as educators and issue makers.

I studied the stories of ranked bodies in Chapter 4. The stories of *ranked bodies* are stories of sick people in financial distress who use crowdfunding sites. Their goal is to build campaign pages and present themselves as someone who is capable of healing and worthy of the funding. In addition, these medical campaign pages need to achieve visibility (ideally, to go viral and trend) so that they can collect funds. Some campaigns will, inevitably, do better than others.

The hierarchies of visibility that govern medical crowdfunding have been amply addressed by academic literature and journalistic media (Scott, 2014; Snyder et al., 2017; Berliner & Kenworthy, 2017; Paulus & Roberts, 2017; Petersen, 2017). This literature reveals that, in medical crowdfunding, the stories that perform best are stories about 'good people' and survivor-like patients who have fallen ill

and for whom health is possible, the only matter being funding. Indeed, sick people who are financially unstable need to perform their deservingness on GoFundMe as a way to access healthcare. I added to these critiques by underscoring how telling personal stories on GoFundMe is an activity also encouraged and governed by GoFundMe's corporate discourse and its changing ranking infrastructures. This involved using the Wayback Machine to trace meaningful changes in GoFundMe's interface and ranking practices.

As I illustrated, crowdfunding sites offer users guidelines for telling specific types of 'restitution' stories (Frank, 2013) and survivorship. Also, across more than ten years of operation, illness stories have been ranked according to freshness (what is happening now matters), sociality (what your social network cares about is what matters), and by trending (what has momentum matters). These practices of ranking are embedded with their own claims about deservingness. Ultimately, in this chapter on GoFundMe, I offered from the outset a critical view on the notion of visibility, edited selves, and ranking practices. Neither YouTube nor Instagram are platforms designed for illness storytelling. GoFundMe, in contrast, has dedicated medical crowdfunding functions and infrastructures that shape people's engagement with illness stories, in ways that recreate long-standing issues of deservingness in healthcare.

The story types and findings I presented—which I distilled from a digital methods analysis of my accompanying case studies—function as 'listening devices' that help sort the threads of online communication and, thus, contribute to the ongoing cultural investigation of illness. Moreover, *popular bodies*, *tagged bodies*, and *ranked bodies* (and their controversies) invite reflection about the place that sick people and people who suffer occupy in culture. Indeed, only a small number of illness stories are made into books and movies and reported by the news. In this mass media regime, as I discussed in the introduction of this book, mostly the stories of celebrities and 'extraordinary' patients achieved visibility. The web and social media, in contrast, made publishing accessible to a broader range of people. Online, illness stories and audiences multiplied. This newfound visibility of ordinary illness stories is a product, at least in part, of the methods embedded in social media platforms. They also invite us to ponder the potential of social-media visibility to make their lives of patients better.

My observations suggest that microcelebrity on YouTube became for Sophia and Daniel a life-line to the world. Vlogging was an activity that they described as meaningful. Both were admired, followed, and invited to events. Recovering one's voice, a concept associated with illness narratives, for Daniel and Sophia had to do with oscillating between their roles as patients and other aspects of their personalities, as well as between what Frank calls 'restitution' and 'quest narratives.' These benefits need, of course, to be understood considering that social media is competitive. For every successful vlogger like Sophia and Daniel, there

are many more whose stories remain unwatched. What makes one sick vlogger more appealing than others warrants further investigation.

On Instagram, bereaved mothers set about to reclaim visibility for their birth narratives. This form of visibility also pushed the boundaries of public illness storytelling. For parents whose experiences are disenfranchised narrative agency came by stepping into their grief and becoming resource and metadata generators, issue-makers, and “wounded healers” – Frank’s (2013) notion for people who share their stories as a means to help others who have similar experiences. To upload a picture of a baby who has died to Instagram will make people uncomfortable but also affirms a person’s identity as a mother. In the case of Instagram, it was not in terms of authenticity, as with Sophia and Daniel, but rather on the basis of inappropriateness that users flagged content and called it offensive.

Medical crowdfunding helps a person recover agency in the sense that it (potentially) allows them to alter their dire circumstances, if everything goes well and the campaign meets its funding target. In a different sense, medical crowdfunding diminishes a person’s capacity to be the teller of their own story. The stories of crowdfunding patients are told out of necessity and demand compromises. The first pertains privacy. According to GoFundMe’s guidelines, it is important that people reveal personal details, including medical bills, diagnosis, and finances. In addition, it is mostly stories about surviving and optimism that do well in the medium. The person in need is best to tailor their story the taste of the audience, leaving feelings of anger and, perhaps, aspects of their lives, untold. The preferences for certain ‘feelings’ remind us of Frank’s and Jurecic’s arguments about the persistence of cure and survivorship ‘at all cost’, and in the case of crowdfunding, at the cost of the capacity to address deeper issues of inequality that go beyond personal experiences and responsibility.

Ultimately, this book has considered how social media supports but can also limit a sick person's capacity to recover their voice as the teller of their own story. Together, the three case studies illustrate how concepts that experts use to theorize illness storytelling —such as voice, agency, ‘searchable talk’, and wounded healing— are informed and complicated by social media’s treatment of visibility. They demonstrate that in the study of social media, illness stories and illness theory cannot be divorced from issues of ranking, popularity, tagging, and audience management. Their interconnection with these issues has significant consequences. Social media has made storytelling available but listening and attention selective and competitive. We will most likely only know the illness of those who are already liked and are media-savvy. Thus, it is necessary that the study of illness stories, as I have aimed to do in my work, develops means to reflect on these implications.

The popularity-driven and work-intensive environments of social media also raise additional questions that follow from my case studies. Do the stories of popular patients create expectations for those who also fall ill? Are they a new *Ars Moriendi* – that is, an instruction for how to die well? Do teenagers with cancer aspire to be like Sophia, perhaps without understanding the work and risk involved? Is this striving something that doctors need to discuss with their young patients, in the same way that school teachers advise on media literacy? Algorithmic visibility also affects those who tell stories. There are networks of helpful users and community. However, there is also the risk of exposure and judgment or of having a platform to speak but not being listened to. If we follow the logic of the medium uncritically, we create inequalities that are algorithmically supported. As illness story researchers, we need to look carefully at social media machines and their conditions of possibility.

In the section below, which is the last in this book, I return to the topic of the health humanities and its digital agenda. With that notion I refer to a discussion about how to best address, from a humanities perspective, how digital and networked media are changing how illness is experienced and told. My goal is to discuss my contributions now in relation to this digital agenda.

Contributing to a digital agenda in the health humanities

Researchers and practitioners, as I also discussed in Chapter 1, have opened up a discussion about the *digital agenda* in the health humanities. For the time being, this debate has been mostly orientated towards the critique and subsequent improvement of digital health technologies. These technologies include medical apps, the use of A.I. in clinical settings, such commercial products as the activity tracker Fitbit, and patient networking sites. When addressing these points, I referenced the work of Kirsten Ostherr (2019) and her concerns about issues of surveillance and control in digital health. I also remarked on Olivia Banner's (2017) call for conducting studies about patient narratives that account for the bio-communicative capitalist conditions of the digital health industry. In her view, one needs to understand patient storytelling as developing in for-profit media environments (Banner, 2017, p.2).

By proposing concepts and techniques to study illness storytelling on social media, I have continued and updated the analytical storytelling tradition in the health humanities. And in doing so, I see my work contributing to a digital health humanities. The argument I have proposed is simple. To understand how illness storytelling develops on social media, one needs to address stories in relation to metrics of popularity and microcelebrity, tagging practices, and ranking cultures. These socio-technical conditions and practices are not secondary but, rather, fundamental to contemporary online illness storytelling. I have provided digital methods techniques for studying the stories of popular, tagged, and ranked bodies.

These techniques are medium-specific and help account for the socio-technical conditions of online stories. These are valuable skill for health humanities researchers interested in social media.

Digital methods like the ones I have used “follow... the medium” (Rogers, 2019) and thus help deal with media (and illness storytelling formats) that constantly change. At the same time, my work echoes the critical concerns expressed by Ostherr and Banner. By theorizing the stories of popular, tagged, and ranked bodies, I, too, have considered how issues of voice, agency, and community are sustained by, but are also in conflict with, the logics of social media. Moreover, I have explored patients not only as victim of such for-profit environments, but also as actively participating in attention and reputations economies by raising funds and self-branding. My readings of illness stories in terms of algorithmic visibility, edited selves, and liveness continue and expand precisely the type of medium-specific critique that health humanities scholarship offers.