Illness online

Popular, tagged, and ranked bodies

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Chapter 1 Introduction: Social Media Illness Stories

I first visited Amsterdam University Hospital in the spring of 2018. I was there to meet with Dr. Hanneke van Laarhoven, a researcher in oncology. At the time, Van Laarhoven was working on setting up a storytelling project, which sought to use art and literature to help patients articulate their experiences with serious illness. The patients would be asked to read a selection of fictional and autobiographical literature. Then, with the help of an artist, they would draw inspiration from the readings and create their own multimedia illness stories. Patients might explore themes, including anxiety about treatment, the daily difficulties posed by disability, and thoughts regarding mortality.

Eager to connect with other researchers working on the subject of illness storytelling, Van Laarhoven had sent an invitation to the local health humanities network to which I belong. The health humanities are an interdisciplinary field, in which perspectives and methods from the humanities are applied to the study of health and practices of healthcare. I replied to Van Laarhoven's invitation and set up a meeting to discuss my interest in studying YouTube video blogs ran by young patients with terminal illness. The content created by these vloggers concerned their lives both in and outside of the hospital. They employ formats such as 'how-to' tutorials, lifestyle advice, and travel vlogging. Also, on YouTube, patients who become popular have dedicated audiences, which comment on their content.

Our mutual interest was sparked by the contrast between the two storytelling formats of multimedia workshops and autonomous vlogging. Van Laarhoven's project had a clear therapeutic goal and experts to guide the storytelling. The benefits of employing literature and art in healthcare settings are, likewise, well-documented. Vlogging about terminal illness is done online for a broad networked audience. It is interactive and motivated by entrepreneurialism and a desire to raise awareness. Intrigued by these differences, we decided to collaborate in digging deeper into these emergent ways for telling stories about illness on social media. To do so, we combined our perspectives, namely, that of the new media scholar and the physician-researcher.

Later that year, I brought these interests to the Digital Methods Summer School. The event is hosted annually at my home institution, the University of Amsterdam. During the summer schools, my job is to train graduate students and scholars in the use of digital methods (Rogers, 2019). These are research techniques that are native to online media. That summer, I assembled my trainees, and with Dr. van Laarhoven acting as consultant, spent a week using digital methods to explore the vlogs of terminally ill cancer patients on YouTube. I was interested in learning more about how illness is communicated through vlogging and how online audiences participate in shaping the storytelling process.

To explore these issues, I employed software tools to capture data and assist me in analyzing a sample of vlogs.

Quickly, it became evident that these vloggers are not only illness storytellers. They are also micro-celebrities who use the affordances of YouTube and social media analytics to create online personas and manage large audiences. Equally, it was clear that the relationship with the audience shapes their illness storytelling in significant ways. For example, viewers grow inquisitive when the vloggers' health declines and they start to upload videos less frequently. This 'silence' provokes worry as much as it raises questions about authenticity. Has the ill vlogger forgotten about their viewers? Did they fake their illnesses to gain attention? As the research came to illustrate, replying to concerned viewers became a part of vlogging at the end of life.

The research-led teaching about cancer vlogs and collaboration with Dr. van Laarhoven during the summer school, served as inspiration for the second chapter of this book. In addition, I reworked a version of this chapter into a short piece, which has Van Laarhoven as the second author. It was published by the medical journal *Lancet Digital Oncology*.

The anecdote above captures the spirit and structure of my doctoral project. My goal is to study how people use social media to tell stories about their illnesses. These stories are emerging objects in the cultural study of illness. They are distinct from written accounts and oral testimonies, which have been investigated extensively by scholars in health humanities, literary studies, and narrative medicine. Social media illness stories reassemble at the touch of a refresh button and are ranked according to popularity. They develop in real-time and on-the-go. And when people share and 'like' them, social media platforms construct networks of stories and people. In turn, all of these activities create digital inscriptions and data that can be captured and studied.

I see an urgent need to investigate how the affordances, procedures, and culture of social media shape how the illness experience is communicated. I ask, what type of illness stories emerge in the always-on and attention-driven environments of social media? What is online illness storytelling affording people who suffer? How to best study their online stories? And further, what is their place in the rising digital agenda in the health humanities?

My answer to these questions comes forth as three types of social media illness stories. The first type is the stories of popular bodies on YouTube. These are stories of patients who engage in micro-celebrity, become popular in social media, and, thus, gain influence. The second type is the stories of tagged bodies on Instagram. These are the stories of people who suffer from disenfranchised conditions and use social media to create 'networked publics' around pain and

loss. To optimize connectivity, these storytellers tag their online communications in unique ways and combinations. The stories of ranked bodies, the third type, are stories of patients in precarious conditions who compete for resources and funding in platforms such as GoFundMe.com. These patients make their private health experiences public in hopes of moving audiences into donating, ranking high on search engines, and going viral. As attention and resources are limited, some patients emerge as 'winners,' while others remain in obscurity.

This typology of social media illness stories is framed by interconnected disciplinary, theoretical, and methodological challenges. The disciplinary challenge has been to reflect on the particularities of studying the illness experience from two perspectives – the broader perspective of the humanities and the narrower perspective of new-media studies scholarship – and then positioning social media illness stories and the types I propose as objects within these fields of knowledge and practice.

My response to this disciplinary challenge takes the form of a literature review. I first address in more detail the scholarship from literary and narrative studies that takes on the subject of illness stories. I give special attention to the work of Frank (2013), Jurecic (2012), and Hawkins (1999), who have themselves proposed types of illness stories. Next I consider the academic treatment of illness stories by such scholars in mass media, digital narratology, electronic literature, and social media such as Rettberg (2019), Papacharissi (2018; 2019), Page (2012), McCosker (2008), Stage (2017), Tembeck (2009; 2016), and Walker Rettberg (2014). This scholarship explores how the affordances of social media platforms and online vernacular practices shape storytelling, which is another key point in my work.

The theoretical challenge was to build on existing theorizing both about illness experiences and social media platforms. To accomplish this, I use the work of illness scholars to analyze each of the types I propose as stories with specific structures and goals pertaining to recovering agency, particularly through ideas of "wounded-healing" (Frank, 2013) and testimonial pathographies. I build upon such concepts by applying them to social media stories through the lens of 'networked selves' (Papacharissi, 2018), 'hashtag publics' (Bruns & Burgess, 2015) and ranking cultures (digital objects handled by the methods embedded in platforms). The result of this theorization, as I mentioned, are three types of social media illness stories; namely, of popular bodies, tagged bodies, and ranked bodies.

The third challenge is methodological. How to operationalize questions about illness and their types into medium-specific, data-driven social media research? Or, more precisely, how to study the stories of popular, tagged, and ranked bodies in ways that align with the medium? Here, I propose "digital methods" (Rogers, 2019). These techniques are native to the web and include, as I explain in more

detail below, applying a 'filtered reading' to the study of vlogs, repurposing hashtags and undertaking co-hashtag analysis on Instagram, and studying the 'website biography' of www.gofundme.com using the Wayback Machine of the Internet Archive.

I bring theory and method together in three case studies. Each describes a distinct type of story, platform, and digital methods research technique. The first case study (Chapter 2) is titled *Popular Bodies: Vlogging at the End of Life*. The research focuses on the YouTube vlogs of Daniel Toms and Sophia Gall, two popular terminal patients who generated millions of views. I use software tools to capture data from the vlogs and explore them in two different ways, each corresponding to a filter and setting on YouTube. First, I read the vlogs chronologically and, then, according to engagement metrics (e.g., number of views) and audience interaction. Daniel and Sophia, as I come to illustrate, spoke about their illnesses and transition into palliative care through the formats of lifestyle vlogging. These include makeup tutorials in Sophia's case, and comedy, in Daniel's. However, while vlogging in these ways was meaningful and helped them regain a sense of agency, online popularity is, with its demand for constant input, at odds with serious illness. Indeed, as their diseases progressed, long periods of silence on the part of the vloggers made viewers suspicious about their authenticity and loyalty.

The second case study (Chapter 3) is titled *Tagged Bodies and Wounded Healers*. It explores how women use Instagram to speak about stillbirth, an experience that is not often publicly discussed and that carries a stigma. This communication takes place through posts, which include images, captions, and hashtags. Hashtags are topic markers that users create by adding the number sign (#) before a word. Hashtags support information discovery and the formation of online communities. To study this networked activity around stillbirth and its controversies, I employ a co-hashtag analysis. The technique involves creating a dataset of Instagram posts on the topic of stillbirth and using software and close reading to explore the communication and tagging practices particular to the stillbirth community. Here, one finds that bereaved mothers use hashtags to direct attention to otherwise disenfranchised experiences and make their grief searchable, networked, and ambient, thus practicing a new form of "wounded-healing" (Frank, 2013). Nevertheless, visibility is risky. Instagram users also 'flag' stories about stillbirth as offensive and as violating terms and conditions.

The last case study (Chapter 4) is *Crowdfunding and the Ranked Body*. Medical crowdfunding is the practice of using crowdfunding sites to raise funds for personal medical treatment. To reach donors, patients create campaign pages and market their personal stories. To study this phenomenon I, first, critique GoFundMe guidelines for campaigning, or in other words, for telling illness stories. Afterward, I use the Internet Archive to articulate a 'website biography' of www.gofundme.com. That is to say, I retrieve archived versions of the website

and describe the different ways in which GoFundMe has ranked medical crowdfunding campaign on its homepage. I see both GoFundMe's storytelling guidelines and its ranking practices as recreating existing issues of inequality in healthcare. Indeed, the analysis illustrates that success (and health) depend on sick people narrating the 'right' diseases and "restitution plots" (Frank, 2013) and proving their 'deservingness.' Also, the medical campaigns that already do well in the medium are prioritized by GoFundMe, thus equating momentum with deservingness.

Chapter 5 holds the conclusions of this book and doctoral project. In them, I reflect on the implications of social media illness stories, specifically, on how algorithmic visibility and online social media affordances enhance but also limit the personal and political potential of illness storytelling. Further, I propose that theoretical and methodological engagement with digital methods, which are key points in my work, open new avenues for health humanities work attuned with online media.

Studying Illness as a Humanities Scholar

Illness and stories

Diseases are pathological events that occur inside the body. They are matters of "physics and chemistry whose presence is betrayed by physical signs" (Jennings, 1986, p.865). Thus, in a biomedical model, "disease is reconfigured only as an alteration in biological structure or functioning" of the body (Kleiman, 1988, p.6). To learn about a disease, one reads test results, medical textbooks, scientific journals, hospital charts, and online medical sources. After diagnosis, in the western medical model, a person usually becomes a patient and pursues treatment. The sick body is managed, and if all goes well, cured.

The term illness describes, in contrast, an embodied and subjective human experience with dimensions of "pain, suffering, and distress" (Jennings, 1986, p.866). According to Arthur Kleiman, professor of medical anthropology, illness encompasses "how the sick person and the members of the family or wider social network perceive, live with, and respond to the symptoms and disability" (Kleinman, 1988, p.3). In his book *The Illness Narratives: Suffering, Healing, and the Human Condition* (1988), Kleiman characterizes illnesses based on the different ways in which they affect a person's life and wellbeing. For example, he speaks of "illness problems," which are the "principal difficulties that symptoms and disability create in our lives" (1988, p.4). These problems may include how pain interferes with a person's capacity to work. Also, an illness problem can be how "the fear of dying brought on by a heart attack may lead to social withdrawal and even divorce" (Kleinman, 1988, p.5).

Similarly, sociologist Arthur Frank characterizes illnesses according to how they introduce uncertainty in a person's relationship with their body and identity. Frank is best known for his book *The Wounded Storyteller: Body, Illness, And Ethics.* The book presents a portrayal of what he calls "remission society," that is, the many people who live with illness and an analysis of their stories within a larger framework of narrative theory. The book was first published in 1993 and the second edition in 2013. Frank like Kleiman is referenced persistently in academic work about illness and storytelling.

After a serious diagnosis, Frank argues, a person may lose control over body functions and memory. For fear of stigmatization, they become vigilant to avoid embarrassing themselves "by being out of control in situations where control is expected" (Frank, 2013, p.31). Pain also transforms the relationship of the person with their body from "tacit or hedonistic" to disconcerting (Frank, 2013, p.34). A sick person may lose energy and appetite or become disabled. For them, the life story once imagined, is no longer possible. For these reasons, illness is described as a "narrative wreckage" (Bury, 1982; Locok, Ziébland & Dumelow, 2009). Indeed, how to plan for the future after receiving a life-threatening diagnosis? How to be with one's own sick body? What to desire? And, amid such uncertainty, how "to avoid living a life that is diminished?" (Frank, 2013, p.xx).

Disease and illness become available to perception in different ways. Scientists measure, quantify, and read diseases in the body and laboratory results. In this sense, "disease is what practitioners have been trained to see through the theoretical lenses of their particular form of practice" (Kleinman, 1988, p.5). Because illness is, in contrast, the subjective experience of the person who is sick, it needs to be self-reported. These first-person reports of illness are called 'illness stories' or 'illness narratives.' In what follows, I introduce and compare these two concepts in some more detail.

Illness stories are told by people "who have had almost any cancer, those living in cardiac recovery programs, diabetics [...] the chronically ill, the disabled, [and] those 'recovering' from abuses and addictions" (Frank, 2013, p.8). We find their stories written in diaries and spoken out loud during consultation and therapy. Consider, for example, how a sick person tells a simple story when answering the question: 'How are you feeling today?' Usually, this person will recount the highlights and difficulties of their day, most likely in chronological order, and report on any symptoms. By doing this, they make their day comprehensible to the interlocutor. Stories can also be profound reflections about mortality. A sick person can strive to tell the story of their life. In that case, the question in need of answering would be: 'Have I lived my life well?'

Medical humanities scholar Anne Hunsaker Hawkins describes illness stories as acts of formulation. They "gather together the separate meanings, the moments

of illumination and understanding [...] and weav[e] them into a whole fabric, one wherein a temporal sequence of events takes on narrative form" (Hawkins, 1999, p.24–25). Hawkins is author of *Reconstructing Illness: Studies in Pathography* (1993; 1999). Pathography is the term that she proposes for autobiographical and biographical accounts of illness, a sub-genre of life-writing.

Mythical thinking is, for Hawkins, pervasive in how people understand their illnesses and write about them. In her view, telling these stories (and their myths) helps sick people to deal with their narrative wreckage, make sense of the illness experience, and recover a sense of control over their lives. Indeed, sick people, Frank also argues, learn "by hearing themselves tell their stories, absorbing others' reactions, and experiencing their stories being shared" (Frank, 2013, p.1).

Outside private and institutional contexts, pathographies are published as books and edited diaries. Some of them are classics, like the essay *On Being Ill* by Virginia Woolf (1926) and *The Cancer Journals* (1980), a collection of diary entries and essays written by black feminist poet Audre Lorde. Other popular examples are *Regeneration* (Barker, 2013), a novel that explores post-war trauma, and *The Diving Bell and the Butterfly* (Bauby, 1997), a memoir about life with locked-in syndrome. Amongst recent best-sellers are *The Fault in Our Stars* (Green, 2012), a fictional love story between two teenagers who have cancer, and *When Breath Becomes Air* (2016). The latter is the autobiography of Paul Kalanithi, a neurosurgeon with terminal brain cancer. *The New York Times* described him as a person "passionately working and striving, deferring gratification, waiting to live, learning to die — so well" (Maslin, 2016, para. 11).

People also practice illness storytelling through the social media that have my special interest – that is, blogs, chatrooms, and social media sites such as YouTube, Instagram, and GoFundMe. Some of these online stories are read widely. This has been, for example, the case with 'My Cancer', the blog of NPR journalist Leroy Sievers (McCosker, 2008), with Lisa Adam's Twitter account and blog about breast cancer (Walker Rettberg, 2016), and with Sophia Gall and Daniel Tom's YouTube channels, which I study later on.

The narrators in illness stories are most often the patients themselves. However, there are other voices too. For example, parents tell stories about their children's illnesses and their role as caretakers (Woodgate, 2006). Likewise, when the disease results in death, it is not unusual for a spouse to finish the patient's autobiography. This was the case in *When Breath Becomes Air* (2016). After Paul Kalanithi died, his wife, Lucy, finished the book. In the epilogue, she narrates Paul's death and recalls his concern about the manuscript. "The manuscript of this book was only partially finished" — Lucy wrote— "and Paul now knew that he was unlikely to complete it —unlikely to have the stamina, the clarity, the time" (Kalanithi, 2016, p.202). Publishing the book became part of Lucy's

mourning process. She describes it as a way for "grieving, honoring him" (Kalanithi, 2016, p.224).

In addition to their therapeutic function, illness stories respond to specific social and historical conditions. Literary scholar Ann Jurecic shares the results of her investigation on these conditions in *Illness as Narrative* (2012). The popularity of the genre, she argues, answers to the "growth of the publishing industry, changed attitudes toward personal disclosure, patient activism about women's health and AIDS, and the rise of the Internet" (Jurecic, 2012, p.18). Other relevant conditions include advancements in science and technology that made the voice of the patient secondary to the clinical report (Jurecic, 2012). Indeed, patients no longer finding themselves satisfied with purely medical understandings of their diseases "want to share their own versions of illness experiences" (Stage, 2017, p.7). Telling stories becomes a way for sick people to reclaim agency as the 'tellers of their own stories.'

Illness and Narrative Studies

Concepts from narrative studies have been particularly relevant for understanding how writers and readers make sense of illness. Narrative has been, in fact, the preferred framework in health humanities research. In narrative studies, narrative is defined as "the representation of an event or series of events" (Abbott, 2002, p.156). The process of narrating is considered to be universal amongst human beings (Alexander, 2003) and "woven in daily life" (Bonell & Hunt, 1999, p.18). Narratives come, for example, "from newspapers and television, from books and films, and from friends and relatives telling us, among other things, that they took the car to work" (Abbott, 2002, p.xi). Legend- or myth-sharing, diary-keeping, autobiographical writing, and blogging can also be examples of narrative activities.

Constructing narratives — or more informally, telling stories— is fundamental to how people make sense of the passage of time and give meaning to their experiences (Mattingly & Garro, 2000). In telling the story, so to speak, people give order and shape to the events of their lives. There is also the notion that "the formation of individual identity [comes] by means of narrative" (Schwalm, 2014, para. 25). That means that our identity and experiences are "very much bound up with the stories we tell about our own lives and the world in which we live. We cannot, in our dreams, our daydreams, our ambitious fantasies, avoid the imaginative imposition of form on life" (Peter Brooks, 2008, p.123).

While the terms 'narrative' and 'story' are often used interchangeably, as I have done above, academic studies do differentiate between 'story' and 'narrative discourse' (Barthes, 1975; Genette 1980; 1988). A 'story' refers to a sequence of events, which have their own chronology and characters. 'Narrative discourse' tells us how a story is ordered and conveyed. The process of narration involves devices such as plot, setting, point of view, temporality, voice, and stylistic choices.

All of these elements help describe, analyze, and compare narratives and thus help researchers move between their uniqueness and shared characteristics.

A study may, for example, set to find patterns and structures amongst texts and theorize a genre. A narrative analysis can also explore how people draw from shared cultural and narrative resources to communicate their experiences. Researchers speak of "master plots" (Porter, 2002), "story skeletons" (Schank, 1990), "canonical stories" (Gould, 2003), and narrative types. They use these terms to describe "stories that we tell over and over in myriad forms and that connect vitally with our deepest values, wishes, and fears" (Porter, 2002, p.42). Amongst them is the Cinderella story, which is a story about a young woman's ascent from adverse circumstances to incredibly good fortune. Another example is Shakespeare's *Romeo and Juliet*, a story of star-crossed lovers whose relationship was marked by bad faith. Stories like these have "enormous emotional capital" and rhetorical impact (Porter, 2002, p.42). They have been adapted many times and are often used to describe actual events. For example, a celebrity gossip website described the marriage between Luciana Barroso, a former struggling bartender, and Hollywood star Matt Damon as a real-life Cinderella story (James, 2016).

Concepts like 'master plots' motivate critical readings. They invite asking, "from what perspective or in terms of what narrative can or will the things that happen to us be made to make sense?" (Puckett, 2018, p.19) Narrative theorizing also helps us to consider whose stories are studied and deemed authoritative and which ones remain silent. This form of critique is present, for example, in feminist and postcolonial literary studies. Ultimately, narrative theory serves as a framework to explore "how stories work and how we make them work" (Garret, 2002, p.1). It concerns plots and devices as well as questions about what people do with stories and what stories do in their lives.

Through a 'narrative lens,' illness stories are accounts of the events that make up a life transformed by illness, as told by the people who experience them. For example, as I mentioned earlier, Hawkins (1988) defines illness stories as a unique literary genre, which she terms pathography. She describes that concept as "a form of autobiography or biography that describes a personal experience of illness, treatment, and sometimes death. 'What is it like to have cancer' or 'how I survived my heart attack' or 'what it means to have AIDS' - these are the typical subjects of the pathography" (Hawkins, 1995, p.1).

Scholars also study illness narratives in terms of story and narrative discourse with an emphasis on "structure, perspective, tone and plot" (Rothman, 1995, p.1). This academic work has flourished around conditions such as cancer, AIDS/HIV, and mental illness, which "exceeded [their] discursive boundaries as a biological

entity and became the focus of intense cultural interest" (Schultz & Stoddard Holmes, 2009, p.xi).

Cancer narratives have become emblematic in literature and "subject to a variety of investigations from a narrative point of view" (Crawford et al., 2015, p.65). Scholarship reveals, for instance, that patients often construct tales of survivorship and heroism and recur to metaphors such as journeying and the military offensive (Skott, 2002). Susan Sontag (1978) believed that these metaphors might do more harm than good. She argued that the symbolic association of cancer with a malignant invasion to the body as well as the use of cancer as a metaphor (e.g. 'corruption is a cancer harming society') lead to social stigma. According to Sontag, "conventions of treating cancer as no mere disease but a demonic enemy make [it] not just a lethal disease but a shameful one" (Sontag, 1978, p.54). In her view, "the healthiest way of being ill is one purified of, most resistant to, metaphoric thinking" (Sontag, 1978, p.3).

There are numerous instances of cancer narratives in American and European literature across different periods in time. These fictional and non-fictional texts have sought to tell "not the story of cancer, but their own individual cancer stories" (Timmermann & Toon, 2012, p.1). Some of these works are touchstones in the fields of literature and medicine. An influential example is the mastectomy letter of novelist Frances Burney (1812). Burney describes her mastectomy (which she underwent without anesthesia) and critiques her treatment by the medical community. In Heather Meek's words, the letter "offers a significant contribution to our understanding of discourses of breast cancer in the long eighteenth century, and to the history of breast cancer more generally" (Meek, 2017, p.27). Another example is Leo Tolstoy's novella *The Death of Ivan Ilych* (1886). The main character Ivan Ilych is a prosperous yet unhappy lawyer who becomes terminally ill. The novella narrates his physical deterioration, loneliness, and fear of dying. It is often used in medical humanities courses to teach medical students "about the feelings of dying patients and the effects of terminal illness on the rest of the family" (Salinsky, 2004, p.119).

In *The Cancer Journals* (1980), which I mentioned earlier, American poet Audre Lorde discusses breast cancer in relation to her identity as a black lesbian woman. The work articulates a feminist discussion of cancer. For example, among various other themes, Lorde reflects on her decision to not wear breast prosthesis despite the social pressure to do so. Edson's play *Wit* (1995) is another well-known cancer story. The main character is Vivian, an English professor with late stage ovarian cancer. The play also explores the objectification of her body and disease both by her doctor and herself, thus offering a critique of the mind-body dualism in contemporary western medicine. Academic books that offer comprehensive reviews of these and other cancer narratives, at least in the context of women's bodies, include *Fractured Borders: Reading Women's Cancer Literature* (2005) and

Mammographies (2013), both by Mary DeShazer. In the latter, she explores ecological, genetic, transnational, queer, and anti-pink discourses in relation to breast cancer.

The AIDS epidemic of the 1980s and 1990s led to a particular proliferation of illness-related literature and art, at least in the United States. The mainstream news media of the time promoted moralist tales about the 'weak and declined' bodies of homosexual men. Infection and spread were dominant tropes. The stories told by the people affected by the disease served as a counter testimony and called on issues of discrimination and silencing. Indeed, these people "published a wide range of writing about their experiences of the disease, as did their doctors, journalists, playwrights, novelists, poets, memoirists, and diarists" (Jurecic, 2012, p.2; Couser, 1997, p.90). Their creative output was an effort "to document the pandemic, create memorial art, and make meaning of suffering and loss on scales ranging from the individual to the global" (Jurecic, 2012, p.2).

In the 1980s and 1990s, HIV/AIDS was associated with a quick and certain death, which, in turn, challenged narrative closure (Kruger, 1996, p.2). In the absence of recovery or quality of life, storytellers wondered, "how, then, one concludes a narrative of HIV or AIDS satisfactorily?" (Couser, 1997, p.91) In fact, closure often only came at the hands of caregivers. "Writers with AIDS" —Greco recalls— "just don't live long enough to make a book out of their experience, or are too exhausted or preoccupied to work efficiently on one" (1989, p.115). While much has improved with regards to the treatment, quality of life, and public perceptions of HIV/AIDS, there is still an inherent risk in speaking/writing publicly about the disease.

Academic work has also been concerned with how mental illness is communicated "textually through deconstructed and destructed form, structure, internal dialogue and narration" (Crawford et. al, 2015, p.43). For example, the 'black dog' is a popular metaphor for speaking about depression. This image capitalizes on the "sinister folkloric history and provides an expressive metaphor for the ghostly, shadowy, and tenacious presence of depression in a person's life" (Bartley, 2009, p.56). There is also a desire to capture how "schizophrenic thought manifests itself in language" (Pies, 1985, p.14). For example, in *Life Writing and Schizophrenia* (2013), literary scholar Mary Elene Wood explores stories written by people who suffer from schizophrenia. These stories, she argues, are written against a backdrop of popular representations of schizophrenia as madness and deviation. In addition, the illness is, often, understood in terms of narrative. Schizophrenia is seen as "a mode of knowledge which interprets the world to be comprised of multiple narratives" (Bukowski, 2014, p.3). This process in which illness is "brought into service to 'stand' for something other than itself" is, in fact, critiqued by Woods (2013, p.3).

Another vivid subject of discussion has been the difficulty of communicating physical pain. In 1926, Virginia Woolf lamented that of the "daily drama of the body there is no record" (1926; 2002, p.33). A schoolgirl, when she falls in love — Woolf claimed— "has Shakespeare, Donne, Keats to speak her mind for her; but let a sufferer try to describe a pain in his head to a doctor and language at once runs dry. There is nothing ready made for him" (1926, p.24). In *The Body in Pain* (1985), Elaine Scarry also explores the ineffable and world-shattering qualities of pain. She argues that "physical pain does not simply resist language but actively destroys it" (Scarry, 1985, p.44). And in *The Language of Pain,* David Biro (2010), a physician turned-patient, recalls his own inability to express the pain he felt. He concludes that we are "convinced that no one else, especially the person in the white coat at the other end of the examining table, could ever understand" (Biro, 2011, p.13).

Biro's investigation departed from this personal 'lacuna' and set to help "sufferers recover their voice and regenerate a rhetoric of pain" (Biro, 2011, p.14). He explores the different metaphorical strategies used by writers such as Toni Morrison and Jack London to speak about pain. These include projecting pain as an external force that attacks the body or as a wound, even when a wound is not presence, as is the case with pain which derives from mental trauma. Underlying this type of research on pain is an interest in finding "a second language that can express what medicine ignores" (Frank, 2011, p.183). This second language "is hard won, and the illness narrative is both the record and the product of winning a coherence that can be called one's own" (Frank, 2011, p.183).

Narrative types as listening devices

A different way of organizing scholarship on illness narratives is not by disease (as I have done above) but according to narrative types. For example, Hawkins (1998) identifies three illness narrative types and master (illness) plots based on the author's intent and myths employed in the storytelling. In other words, she proposes a classification according to how people address the "need to communicate a painful, disorienting and isolating experience" (Hawkins, 1998, p.10). The first of her types is the testimonial pathography, which communicates what it is like to be ill. Testimonial pathographies have didactic intentions, which is to say, authors tell and publish them with the intent to educate other people. In angry pathographies, the second type, a person speaks about the injustices experienced during their time as a patient. These stories have a denunciatory intent. The last are alternative pathographies, which advocate for treatments outside the medical establishment.

To differentiate illness narratives, Jurecic, instead, departs from people's "increasing awareness of statistically calculated risk" (2012, p.18). Her goal is to study "how writers and readers use narratives of illness to make meaning of the

experiences of living at risk, in prognosis, and in pain" (2012, p.4). For example, nowadays it is not unusual for people to learn about potential illnesses after genetic testing. The narratives that result from this knowledge are about people living their lives "by the numbers" (Jurecic, 2012, p.20). Also, after a diagnosis with a low probability of survival, narratives of heroism surface. In them, people see themselves as fighting to beat the odds.

Arthur Frank also proposes a typology of illness narratives. He differentiates narrative types based on plot and how patients deal with problems of embodiment — "control, body-relatedness, other-relatedness, and desire" (Frank, 2013, p.76). The first of his types is the restitution narrative. In this narrative, the sick person's goal is to achieve health. Their illness experience is made meaningful by adhering to biomedical models, following treatment, and charting improvement. Following treatment — and telling the story— helps the patient regain a sense of control over their body. Thus, restitution is the story of a disciplined body. Both Jurecic's ideas about calculation and Frank's concept of restitution will be relevant for understanding medical crowdfunding — a topic that I discuss in Chapter 4.

In chaos narratives, the second of Frank's types, illness is experienced as cycles of misfortune. Chaos is the opposite of restitution: "its plot imagines life never getting better" (Frank, 2013, p.97). The forces of chaos are contingency, isolation, lack of desire, and dissociation between the person and their body. The story is thus also fragmented, loops on itself, and the narrator is overwhelmed. Because of this 'static' condition, it is an "anti-narrative" (Frank, 2013, p.98). This 'chaotic body' cannot accept help or imagine a different outcome.

The third is the quest narrative, which follows the form of the hero's journey. This is the quest of a sick person who decides to meet suffering head-on, accepting uncertainty and seeking to use it (Frank, 2013, p.155). Underlying the turning point in this type of illness narrative is the belief "that something is to be gained through the experience" (Frank, 2013, p.115). While traditionally heroes earn their boon by force, in illness stories, the boon is earned through perseverance and vulnerability. Instead of Hercules, one finds a bodhisattva (Frank, 2013, p.216).

The quest is also the story of the communicative body, which is "not only an ideal type but also an idealized type" (Frank, 2013, p.48). Unlike the disciplined body of the restitution narrative, the communicative body accepts uncertainty. It desires to learn to avoid "living a life that is diminished" (Frank, 2013, p. xvii). The person suffering from a chronic condition may, for instance, ask: what is to be gained from the wreckage? This could mean pursuing goals that extend beyond cure such as raising awareness and activism. Ultimately, in Frank's quest narratives which aim beyond to see beyond, the sick person becomes a wounded-healer who may "care for others" (Frank, 2013, p.xii). Critiques to the ideology of

cure, which presuppose a return to a normal state, are also found in work on disability and illness. A relevant example is Eli Clare's book B*rilliant Imperfection* (2017). Clare addresses, amongst other topics, his experience as a man with cerebral palsy and encounters with ableism and medicalized versions of her disability. That is to say, as something that needs to be *cured*. I return to the concepts of the quest, communicative body, and wounded healing and cure in Chapter 3, when studying the Instagram activities of women who have had a stillbirth.

Reading and theorizing first-person illness stories, as the authors above have done, requires special considerations. On the one hand, people feel "passionately, that their stories are uniquely theirs and that feeling deserves respect" (Frank, 2019, p.10). On the other hand, as the literature I have also reviewed illustrates, we build stories from common materials and cultural resources. In fact, "what can be told, how it can be told, depends on those already-there materials" (Frank, 2019, p.10). The issue for practitioners and researchers is then to "preserve—indeed, honor—the individual specificity of each story while saying something about the immanent order of the corpus of stories and its moral imperative" (Frank, 2019, p.9).

A balance between specificity and generalization is accomplished, according to Jurecic (2012), by practicing a hermeneutic of listening. Jurecic sees this mode of reading/listening already at work in health humanities-oriented scholarship and, specifically, in the work of researchers such as Hawkins and Frank. However, 'listening' does often stand in contrast with mainstream literary academic criticism, which meets stories of suffering mostly with a "hermeneutics of suspicion" (Jurecic, 2012, p.3). Here Jurecic is building on Paul Ricoeur's (1970) concept of suspicion. Ricouer employs the concept to describe a process of interpretation and critique characterized by the desire to 'read between the lines,' and move beyond self-evident truths. Suspicion is, however, for Ricoeur only one side of a "double motivation: willingness to suspect, willingness to listen" (1970, p.27)

Jurecic claims that suspicion has become synonymous with contemporary academic critique, leaving behind its counterpart, listening. For example, artworks about an author's illness may be quickly dismissed as untrustworthy, sentimental, amateurish, and as examples of 'victim art.' A hermeneutic of suspicion can also manifests itself in the impulse to read illness narratives exclusively in terms of ideological forces acting on patients/narrators. For Jurecic, this situation is the academic equivalent of compassion fatigue, that is, an incapacity to engage and be moved by people's suffering (e.g., see Joinson [1992] and Moeller [1999]). The way forward is to recover a 'willingness to listen'.

To continue unpacking this invitation to listening, Jurecic refers to Bruno Latour's critique of critique (2004). For Latour, critique is too concerned with debunking facts and explaining social phenomena. The protagonist in this account is an all-knowing academic who imposes order. As an alternative, Latour suggests that we study matters of concern, which are entities in-the-making. The latter demands that we listen to how actors speak and give meaning to their own actions and how the available (narrative) resources come alive in their hands.

Indubitably, more interesting than 'debunking' illness stories is asking, what do people do with pre-established story types? How do they create new resources and build new assemblages of people and stories? Is lived experience at odds with our beloved master plots? The questions above are not inconsequential. As Frank also remarks, "telling your story according to the default narrative is fine... as long as that narrative fits the circumstances of your life" (Frank, 2019, p.11). Narrative wreckage, from this perspective, "is the condition of trying to understand one's life according to a narrative that doesn't fit" (Frank, 2019, p.11).

Underling the previous discussion about suspicion and listening, is also the issue of truth-value with respect to illness narratives. The process of ordering and creating involved in telling stories inevitably mediates between "an inner world of thought and feeling and an outer world of observable actions and states of affairs" (Mattingly & Garro, 2000, p.1). One might question if the way a patient speaks or writes about their illness is accurate. Likewise, when telling their story, a person might adhere new meaning to a past event. For example, they can come to use a positive tone when speaking about a difficult period in their life. They may come to see it, with time, as a period of rebirth.

A practice of listening, thus, involves recognizing the value in processes of ordering and reconstruction. In Frank's words, "the truth of stories is not only what was experienced, but equally what becomes an experience in the telling and its reception" (Frank, 2013, p.22). Illness is, after all, the experience of a self in crisis, thus "neither a self as fiction or self as an ineffable mystery," Hawkins argues, "are adequate formulations for the self encountered in pathographical narrative" (1998, p.17).

Taking these arguments about listening into account, narrative types, as the ones proposed by Frank, Hawkins, Jurecic, and the ones I propose, are not meant to reduce or subdue the individual voice. Rather, types and concepts serve as listening devices and entry points into complex experiences. Indeed, types of "illness stories mix and weave different narrative threads the rationale for proposing some general types of narratives is to sort out those threads" (2013, p.76). Concepts such as 'restitution plots' and 'disciplined bodies' "can help us in recognizing what basic life concerns are being addressed and how the story proclaims a certain relation of the body to the world" (Frank, 2013, p.24). In actual

telling, however, one must remember, the types are "perpetually interrupting" each other (Frank, 2013, p.76). Listening is, in this sense, also about recognizing that, just like narrative, research always frames.

Applied Narrative and Other Interventions

Academic research on illness narratives, as the work that I have reviewed in the previous sections, helps understand illness as a complex personal and cultural experience. According to health humanities scholar Paul Crawford, the insights gained through this academic work and the scholarly methods employed in it can, in addition, lead to interventions in the lives of people living with illness and in healthcare settings. The argument here is that humanities-based work can support "more richly-textured ways of understanding healthcare as practice" (Crawford et al., 2015, p.6).

Now, based on the research by Crawford and others, I wish to address the application of these ideas of narrative in healthcare settings in activities such as "poetry workshops for patients or narrative medicine training with medical students" (Klugman & Lamb, 2019, p.6). Afterwards, I will briefly address other fields (anthropology, cultural studies, and history) that are also significant to the cultural study of illness and their respective applied proposals. This present section is the last step in creating a disciplinary context for illness stories as objects of cultural study and before arriving to the more specific work on illness and media, which is, ultimately, the core interest of this book.

I have mentioned two examples of applied literature in healthcare settings. In the first example, a poetry workshop, patients learn to express themselves and craft stories around their experiences. I began this book with an anecdote about a similar type of workshop. Dr. Hanneke van Laarhoven, a researcher oncologist from Amsterdam University Hospital, as I wrote earlier, was setting up a project to help cancer patients tell their own stories. These patients were meant to read literature and, then, use the insights from those readings to collaborate with an artist and create their own personal narratives. In the poetry and storytelling workshop setting ideas about the meaning-making capacities of narrating and the agency that derive from it are put into action and deployed for their therapeutic benefits.

In the second example, training in medical narrative, medical professionals turn to "humanities and arts to broaden and deepen their understanding of the illness experience" (Stewart & Swain, 2016, p.2586). A well-known example of such training takes place in Columbia University's program in narrative medicine. The program introduces medical students to short stories, prose poems, memoirs, novels, and films. Through studying these texts, they learn how illnesses are plotted and represented and thus they gain such skills as "respecting multiple perspectives, hearing and mediating competing voices" (Charon, 2006, p.8). These

forms of literary and listening competencies help healthcare practitioners become more "attentive to a persons' lived experiences and truths, honouring uniqueness in respecting different ways of living a situation" (Naef, 2006. p.147).

Narrative skills and critical approaches to life-writing can also help practitioners "understand and critique the social aspects of healthcare and to try to effect change in healthcare" (Crawford, 2019, p.40). For example, fiction writing is used as "a research methodology that illuminates deep-seated feelings, attitudes, and beliefs about stigmatized health conditions, social or cultural groups, or unsympathetic health behaviors" (Saffran, 2019, p.268). In a workshop on fictional writing, for example, healthcare personnel may be asked to describe characters and scenes so that they "must put him- or herself in another person's shoes" (Saffran, 2019, p. 268).

The role of creative writing and literary analysis in medicine must, nonetheless, be approached with caution. Specific stories and metaphors become romanticized while others are dismissed, sometimes missing a more "grounded approach to understanding the cultural specificity of idioms of distress" (Woods, 2011, p.74). For example, the widespread use of the metaphor of the body as a battlefield has been criticized for excluding patients who can no 'longer fight'. In this case, it becomes evident that "while stories can be vehicles of contestation, opposition, and self-empowerment, they can also act as vehicles of oppression, self-delusions, and dissimulation" (Gabriel, 40, p.169). I touched on these arguments already when discussing Susan Sontag's (1974) and Wood's (2013) critique of metaphoric thinking and Clare's (2017) views on the ideology of cure in relation to disability.

Programs in narrative medicine also boast other potential problems. They can draw from a homogeneous pool of personal stories, for instance, and thus replicate biases (Banner, 2017). In doing this, they fail to generate the infrastructural awareness which is needed to address issues beyond individual patients such as discrimination and racism in healthcare. In addition, there is also the critique of the universality of narrative and its status as beneficial (Woods, 2011; Hyvärinen, 2011). A fixation on one type of coherent life story, which is deemed desirable and acceptable, can very well limit a person, instead, of empowering them. Indeed, "can narrative coherence be a harmful phenomenon, how, and in which context?" (Hyvärinen, 2011 p.7) A related question is that of lacunas: what other forms of expressions and ways of being, which do not crave a sense of continuity, are missing?

Other Perspectives

I have, so far, explored illness storytelling in relation to literature and narrative studies and presented a brief overview of an applied agenda, which includes deploying patients' creative storytelling capacities, using literature to enhance listening competencies in doctors, and fictional writing to create reflexivity.

Before we continue it is helpful to point out that, within the humanities, health and illness are objects of investigation in a variety of other fields. These include cultural analysis, anthropology, "philosophy (in addition to bioethics) [...] media studies, religious studies, American studies, African studies, Asian studies, art history, classics, comparative literature, European studies, history, history of medicine, women's and gender studies, Latin American studies, LGBTQI studies, disability studies, [and] age studies" (Berry, Jones & Lamb, 2017, p.1).

These additional humanities approaches also have important things to say about illness stories. Anthropology helps conceptualize illness narratives as distinct across cultures, for instance. These narratives "tell us about the way in which cultural values and social relations shape how we perceive and monitor our bodies" (Kleinman, 1998, p.xiii). Cultural analysis has contributed to the notion that illness belongs to ideological constellations. In *Medicine as Culture* (2012a), Deborah Lupton examines, for example, the culture of western medicine and the meaning of the body within it. She describes the body "as a social construction, vulnerable to ideological shifts, discursive process and power struggles" (Lupton, 2012, p.20). In doing so, Lupton seeks to understand why "health and illness are surrounded with controversy, conflict and emotion" (Lupton, 2012, p.viii). One also finds cultural analysis about "medicalization," which is the "process by which human problems are turned into treatable diseases and brought under the purview of medicine" (Cole, Carlin, & Cason, 2015, p.41). Medicalized experiences include infertility and childbirth (McIntosh, 2012) and death (Hall, 2019). Classic genealogies on similar subjects include Foucault's *Madness and Civilization* (1961; 2013) and *The Birth of the Clinic* (1963; 2010). These works have contributed to the understanding of institutional control —"biopower" (Foucault, 1963)— over sick and healthy bodies.

While my case studies on social media illness stories are not anthropological or examples of cultural analysis *per se*, I do employ literature from these fields and embrace their calls for reflection. That is to say, I am mindful of the fact that my work addresses western medicine and western ideas about disclosure. Likewise, the illness stories and media environments that I study have cultural dimensions. For example, in Chapter 3, which explores communication about stillbirth on Instagram, I employ work from medical sociology and cultural studies to contextualize stillbirth as a disenfranchised phenomenon. Likewise, in Chapter 4, I address medical crowdfunding as a practice shaped by the unique conditions of the current American healthcare system and 'survivor culture'.

Another helpful field of inquiry into illness narration consists of histories of medicine. For example, in *Medical Humanities: An Introduction* (2015), Cole, Carlin, and Carson offer an overview of the history of medicine, which they describe as "the oldest discipline of the medical humanities" (Cole, Carlin & Carson, 2015, p.21). The history of medicine is often written in terms of the transformation of

perceptions of disease, healing, death, and doctoring across different periods. These periods include antiquity ("the pinnacle of ancient Greek medicine" [Cole, Carlin & Carson, 2015, p.27]), medieval medicine, medicine in early modernity, during the enlightenment, modern medicine, and contemporary medicine. These later periods account for the field of medicine that we associate with hospital training and scientific methods.

Teaching history was perceived as part of the moral training of doctors and, later on, in the context of 1970s American and European education, as an 'antidote' to "the dehumanization of medicine" (Cole, Carlin & Carson, 2015, p.22). This new generation of historians looked "beyond the great books of medicine to explore issues of power, race, class, and sex in the delivery of healthcare" (Cole, Carlin & Carson, 2015, p.23). These new works emerged, like literature, also around specific diseases. Tuberculosis is explored, for example, in *Living in the Shadow of Death*, a book authored by public health historian Sheila Rothmann (1995). A similar case is *The Emperor of All Maladies: A Biography of Cancer* (Mukherjee, 2011), a book that tracks "the first historical glimpses of the disease, the development of treatment regimens" (Klein, 2011, para. 4).

Historians also write about movements and contested practices such as birth control and their relationship to mass media in the United States. That is the case in Manon Parry's *Broadcasting Birth Control* (2013), which explores the "extensive use of mass media to build support for legalization and then publicize the idea of fertility control and the availability of contraceptive services" (Parry, 2013, p.1). Parry discusses, for example, the use of 'pictures with a purpose' by earlier advocates of the time, highlighting how the association of sexual liberation with birth control was traditionally downplayed in exchange for the acceptability of 'family.' The medium, Parry argues, shaped the message and the movement. While I am not partaking in historical research with a focus on media in the same way that Parry, I am interest in tracing and contextualizing changes in media, specifically in Chapter 4, when I present a website biography, a form of history, of the crowdfunding platform, GoFundMe.

Anthropological, cultural, and historical studies have influenced healthcare theory *and* practice. For example, the concept of 'ritual' has helped understand and re-imagine care (Currie et al., 2018). Similarly, anthropological studies are used to teach cultural sensitivity and cross-cultural communication in clinical contexts (Hsieh, Hsu & Wang, 2016). Lerner, who wrote about celebrity patients, and whose work I address later on, reflects on the usefulness of history for the medical profession. He argues that "history reminds us that medicine has been— and always will be—a social process" that includes power, class, and race (Lerner, n.d., para. 1). For example, one must not easily forget that "researchers routinely enrolled vulnerable and unsuspecting populations into potentially harmful

experiments [...] Telling these stories to modern students, clinicians and patients can prevent such abuses from happening again" (Lerner, n.d., para. 3).

In the next section, I focus on the study of illness stories from the perspective of media scholarship. More pointedly, I review scholarship that brings together illness with mass media, specifically television and confessional journalism. Next, I address electronic literature on the subject of illness, which is literary writing that explores the possibilities of the computer, as found in genres such as hypertext fiction and games. Then, I review work on illness stories and networked selves on the web and social media. This last cluster involves the work of scholars who have theorized non-literary forms of storytelling about illness which are native to the web and are studied with concepts such micro-celebrity and blogging cultures.

This will be a crucial point in my argument and, thus requires, further clarification. Mass media representation of illness, electronic literature, and online stories are not presented historically. I do not claim that electronic literature follows mass media or that it is an antecessor to illness storytelling on the web and social media. The types of illness stories which I propose (stories of popular, tagged, and ranked bodies) are not 'new' electronic literary pathographies. Instead, mass media, electronic literature, and online illness stories are three possible pathways that an investigation, such as mine, concerned with illness stories and media studies could take. I explore the first two paths, mass media and electronic literature, relatively briefly. My intension is to recognize the relevance of academic studies on television, celebrity culture, and journalism that touch on issue of illness narrative. With a similar intention I review key pieces on electronic writing on illness and use this to hint to what could be, in itself, a separate book. Then, I follow and commit to the third pathway: illness stories on the web and social media. This section is vital to continue positioning my own work on social media illness stories, which belongs to this subfield of academic media research.

In writing this media-focused sections I also responds to a disciplinary gap. I have found the contributions of media studies scholarship somewhat underrepresented in reviews and books about culture and illness and the health humanities. An example is Crawford's book, *Health Humanities* (2015) which includes chapters on narrative, literature, anthropology, linguistics, and art. It seems to lack a chapter on media studies.

This gap cannot be due to a lack of urgency. Addressing the intersections between illness and media and social media more specifically is, with time, only becoming more relevant. In fact, there is a need for illness studies with "a new kind of emphasis on the digital and the visual" (Ostherr, 2013, p.7) and a need to develop practices of listening and applied research aligned with "new technologies and

ways of knowing" (Ostherr, 2013, p.12). It is also in hopes of beginning to bridge this gap, that I present the following overview and my own research contributions.

Studying Illness as a Media Scholar

Mass Media and the Representation of Illness

Several primetime series feature physicians as main characters and dramatize hospital life. This has been the case in the drama series 'Grey's Anatomy,' which since its premiere in 2005 has followed Meredith Grey's journey from intern to a seasoned surgeon. Soap operas, meanwhile, advance storylines by having characters fall ill. Talk show hosts discuss trendy medical treatments and reality television follows the lives of unconventional patients. For instance, 'My 600 Hundred Pound Life' is a popular show about the weight loss journeys of morbidly obese people in the United States. Popular media, as this short list illustrates, incorporate both the fictionalized illness stories of patients and doctors as well the documentation of real cases by television producers and journalists.

Academics have critiqued these representations and studied how audiences make sense of them, especially, when "controversial bioethical concerns interact with media events" (Friedman, 2004, p.10). The book *Playing Doctor: Television, Storytelling, and Medical Power* (1989; 2010) by Joseph Turow is a well-known study of 'medical television'. Turow explores the figure of the 'heroic doctor' in American media, since the 1950s until the 2010s. Put "into storytelling terms", it is a study of "settings (hospital, private offices), characters (surgeons, physical therapists), and plots (operations, patient phone calls) that might describe everyday activities of the medical system" (Turow, 2010, p.2). The type of stories told with these narrative elements, nevertheless, have changed. The overly positive depictions of early television doctors have given way to stories about the troubled personal lives of physicians.

Similarly, *Cultural Sutures. Medicine and Media* (2004), edited by film and medical humanities scholar Lester Friedman, explores print, advertisement, fiction films, television, and documentaries. The book deals, for example, with the treatment of assisted suicide by the news media and, specifically, with the controversy that followed the airing of a segment on Dr. Jack Kevorkian by the news television program '60 Minutes'. In this segment, audiences saw Kevorkian performing the voluntary euthanasia of a terminally ill 52-year-old man. Hospital television dramas, the broadcasting of medical procedures, and the effects of installing television sets in hospitals are also discussed in the book.

In *Medical Visions. Producing the Patient through Film, Television, and Medical Imaging* (2013) Kirsten Ostherr argues for the importance of a medical humanities that engages with image-based narratives. Hospital dramas and medical advertisements, like

the one already addressed by Turow and Friedman also feature in Ostherr's book. She adds to the repertoire medical imaging technologies (e.g., MRI machine) and their use in storytelling. For example, television shows have a preference for narrating rare health conditions. This requires showing what occurs inside of the body and explaining complex scientific concepts. In these instances, medical imaging such an MRI and 3D animations of biological processes enhance "the dramatic potential of story lines about rare conditions" and are key for telling a diagnosis (Ostherr, 2013, p.21). The latter "is essential to the production of narrative closure, which, in turn, is essential to a satisfying viewing experience" (Ostherr, 2013, p.21). I address Ostherr's work in more detail when discussing digital health, later on this chapter.

Media-focused critiques like Turow's, Friedman's and Ostherr's are important since "mass media portrayals contribute to the creation or reproduction of knowledge about illness and disease, doctors and other medical workers and medical treatments" (Lupton, 1999, p.259). These portrayals function as 'master plots' and myths, that is, stories with great rhetorical power, that shape people's perception of medicine. For example, medical interns use television doctors as referents of moral character (Vandekieft, 2004) and pop culture models for viewers "the ideal modern patient" (Treichler & Reagan, 2007, p.5). The media represent some patients as innocent victims and others as deserving of their fate. Studies have explored this depiction of deservingness, for example, in relation to postpartum depression, mental health, euthanasia, AIDS, and reproductive health (Klin & Lemish, 2008; Cross, 2004; Dubriwny, 2010; Packer 2017; Jones, 2004; Herold, 2018; Curato & Ong, 2004; Wilson, 2012). In Chapter 4, I return to the issue of deservingness, not in terms of representation *by* mass media, but in terms of self-representation by crowdfunding patients.

Research has also revealed that films and television tend to favor portrayals of recovery plotlines (such as those studied by Arthur Frank) or the more extreme aspects of illness. Indeed, Hollywood prefers a violent death over more realistic depictions of the terminal stages of life (Gallagher, 2009). Likewise, news magazines are likely to present illnesses in relation to medical triumphs (Wagner, 2000), and there is an "emphasis on cancer as an opportunity for personal growth in cinematic portrayals of the disease" (Ristovski-Slijepcevic, 2013, p.629). The latter evokes the concept of the illness quest, also proposed by Frank.

Illness stories also intersect with a different aspect of mass media: celebrity cultures. A well-known work on the subject is Lerner's (2009) history of the celebrity patient *vis a vis* American tabloid culture. Lerner offers an account of the stories of twelve celebrity patients, including baseball player Lou Gehrig, who died in 1941 from amyotrophic lateral sclerosis. Gehrig's illness created a dilemma for sports journalists at the time. In order to give a 'good death' to their beloved athlete, these journalists chose to downplay the severity of the illness. Such a

rationale stands at odds with today's carnivorous tabloid culture. While Lerner is a medical historian, his work attends closely to media dynamics. A similar example is Manon Parry's research about the American birth control movement and the mass media, which I referenced earlier.

Lerner also wrote about ordinary patients and caretakers who became famous. Such was the case of Augusto and Michaela Odone, whose son Lorenzo suffered from Adrenoleukodystrophy (ALD). Frustrated with the prognosis and the lack of options available to them, the couple took to research and developed a homemade remedy, which allegedly helped their son. The story of these committed parents was adapted into the Hollywood film 'Lorenzo's Oil' (1992). Ultimately, Lerner argued, "just as celebrities could define popular tastes in clothes, food, and style, so, too, could they demonstrate how to be a successful patient" (2009, p.270). The Odone's story, in his words, illustrated a parallel dynamic: "ordinary patients were now supposed to act like ill celebrities — not starting foundations, necessarily, but becoming knowledgeable and fighting their diseases" (2009, p.271).

Beck et al. (2015) followed in Lerner's footsteps. In their study of contemporary celebrity health narratives, they find that narratives are co-constructed between the news media, celebrities, and their fans. As a type of illness story, the stories of sick celebrities do not come forth as finished narratives or examples of agency. Their stories are 'followed' and reported by the media as they developed, often against the celebrity's wishes. The dynamic changes after the celebrity recovers and publishes a memoir or when they give interviews to tell *their* side of the story.

Beck et al. also conclude that celebrity's health narratives have the potential to stimulate public interest on particular diseases. A similar premise underlies entertainment education, which seeks to educate on "health and social issues by incorporating them in the storyline of prime-time television shows or daytime soap operas" (Glik et al., 1998, p.264). Amongst such instances of health education, Beck et al. are especially interested in cases that blur the boundaries between entertainers and patients — for example, when an actor's disability or medical intervention becomes part of their character and is aired (Beck et al., 2015, p. 128). An early case took place in 1984 in American television. Both the actress Jeanne Cooper and the character she played in the soap opera, The Young and the Restless, had a facelift. The showrunners included the actual footage in the episode and premiered it. This is referred to as television's first reality show moment (Logan, 2013). I return to these dynamics of 'liveness' and fame in Chapter 2 when studying the vlogs of two micro-celerity patients, that is, of patient who are Internet famous.

Scholars have also written about investigative and confessional journalism as a site for illness stories. Investigative journalists, for example, have a history of exposing (and telling the story of) abuses committed inside healthcare facilities.

The Archive for Undercover Journalism at New York University (NYU) hosts a collection of such exposures. One of the earliest cases is the work of reporter Nellie Bly, who in 1887 faked 'insanity' and had herself committed to a state institution in New York. Once there, Bly experienced first-hand the until-then rumored violence and starvation. Her investigation led to a series of articles and, later in the same year, to the book *Ten Days in the Madhouse*. Bly's book served as evidence to support the demand for changes in the treatment of the mentally ill in the state of New York.

Television has had its own examples of medical exposé. One of them was Geraldo Rivera's 1972 report on the Willowbrook State School for the disabled, located in the state of New York. With the help of a school employee, Riviera broke into the institution and recorded numerous unclothed, soiled, and restrained patients. The evidence of their inhumane treatment was aired as the television documentary *The Last Great Disgrace*. According to the director of the archive at NYU, stories like these "are meant to give voice to the silenced or the stigmatized" (Kroeger, 2012, p.190). They "often have an implicit it-could-happen-to-you dimension" (ibid., p.172).

Confessional journalism, "which refers to highly personal columns revealing private details of the columnist's life" (Zelizer & Allan, 2010, p.22), also takes illness as subject. For example, Rosalind Coward (2014) studied "cancer columns", which are columns authored by sick journalists who engage in public "diary-like writing about facing mortality" (p.4). This form writing fits easier in the traditional definition of illness story, namely, a story told in the first-person by someone who is sick. However, unlike a published pathography, cancer columns are delivered serially. The reader learns about the circumstances of the journalist as they develop. The figure of the sick journalist also opens up the question of influence, that is, in this case, a question about whose stories (and ways of being ill) enjoy visibility and to what effects. Coward sees cancer columns, for example, as encouraging "readers to think differently about illness" and serving as contemporary form *Ars Moriendi*, that is, as examples or guides for how to face death (Coward, 2014, p.10).

Based on the aforementioned selected examples, it can be argued that mass media scholarship, understood broadly, has contributed to the insight that illness is a matter of mass mediation and popular culture. In other words, it is important for patients and healthcare professionals to understand that mass media also mediates them. By saying that I mean that the perception of the profession of medicine, the behavior of doctor and patients is shaped by popular media representations. The same mass media researchers argue for a health humanities that can acknowledge "cinematic medical gazes" (Friedman, 2004, p. xx) and a "broader understanding of narrative textuality that includes the multiple, heterogeneous

sites and media through which patients and doctors collectively produce meanings about health and disease" (Ostherr, 2013, p. 9).

In the next section, I leave the world of television and printed media behind and engage with electronic writing about illness. How are authors writing about illness with and through computers? One may think of these works of hyper-text fiction and games as continuations of (and breaks from) the book-form pathography.

Electronic Literature and illness

Electronic literature is a field of creative experimentation and research into forms of writing that explore the capabilities of computers and networks. These literary works are composed using digital images, text, sounds clips, hyperlinks, and digital animations. They are coded and powered by algorithms. One 'reads' them by navigating, 'clicking,' and playing. Genres include hypertext fiction, game-like narratives, and network writing.

Electronic writing, according to literary scholar Katherine Hayles, calls for media-specific analysis. That is to say, a form of analysis that rearticulates "legacy concepts [from literary studies] in terms appropriate to the dynamic of networked and programmable media" (Hayles, 2008, p.51). When examining a work of electronic literature, for example, one departs "from the language of the text to a more precise vocabulary of screen and page, digital program and analog interface, code and ink [...] computer and book" (Hayles, 2004, p.2). This form of analysis also considers the technology and systems employed in the production of creative works. Electronic literature is, after all, created with software and published on websites, game consoles, and platforms like Twine. The latter is a platform that "allows users to construct hyperlinked text-based games with little or no programming experience" (Kerr, 2015, para. 3). As digital artist and researcher Scott Rettberg phrased it, one needs to read "the poetics and language" of a piece electronic literature as much as "their structures, rules of operation, platform, and algorithms" (Rettberg, 2019, p.13). Electronic literature, inevitably, brings together issues of writing with the study of platforms (Montfort & Bogost, 2009).

In my overview of the field, I build on the work of Rettberg (2019) as well as other scholars including Montfort (2005), Ensslin (2007), and Hayles (2008) to contextualize examples of electronic literature on the subject of medicine and illness. Specifically, I discuss hypertext fiction works such as 'Patchwork Girl' (1995), 'Reagan's Library' (1999), and 'Queerskins' (2012), games like 'Depression Quest' (2013) and 'That Dragon Cancer' (2016), and mobile phones novels. While these artistic works have different pragmatics and aims than the stories that I examine they do invite reflection and analysis on how medium-specific qualities of networked media and immersive environments can be employed to write about illness.

The first genre I draw attention to is hypertext writing. It involves "writing stories designed as interlinked fragments of text, with multiple possible reading sequences to be navigated through the reader's selection of links between them" (Rettberg, 2019, p.54). This compositional structure sets hypertext apart from traditional printed literature. In fact, according to game scholar Astrid Ensslin, hypertext is un-printable. Such an act "of material linearization would disrupt its characteristic underlying macrostructure" (2007, p.5). Moreover, hypertext readers are released from the dominance of the author. They become 'wreaders' who, by interacting with the text, also write it (Landow, 1992). The result is a reading experience that is highly individualized and fragmented.

Both Rettberg and Ensslin include 'Patchwork Girl' by Shelley Jackson in their review of canonical works of hypertext literature. 'Patchwork Girl' is a feminist re-telling of the novel Frankenstein by English author Mary Shelley. In the classic tale, doctor Frankenstein uses parts from different female corpses to create a companion for his male monster. However, horrified by her look Frankenstein destroys her. Scholars of literature and film have discussed Frankenstein in terms of the politics of disability and the production of the human body as spectacle in negotiation with social and medical discourses (Clarke, 2004; Pheasant-Kelly, 2018).

In Jackson's electronic version, the female monster is rescued and reassembled by a fictionalized Mary Shelley. Readers experience the story by navigating through interconnected sections, fragments of text, and images of the creature's body. Clicking on the different parts of her body, for instance, directs readers "to lexias telling the women's stories from whose parts the monster was assembled" (Hayles, 2000, para. 27). Her body and identity are 'sewed' back together through the act of reading. Accordingly, the themes of scaring, reproductive technologies, and decomposition acquire significance and a critical edge as the story advances. 'Patchwork Girl' is, ultimately, an electronic tale about the "difficult feelings of being made, not born" (Sundén, 2008, p.161).

'Reagan's Library' by Stuart Moulthrop, another canonical work of hypertext fiction, deals with the subjective experience of disease. The title references American president Ronald Reagan, who was diagnosed with Alzheimer's in 1994 and rumored to have suffered from it while in office. The piece integrates QuickTime VR panoramas, sounds, and "generative (and degenerative) text fragments" (Rettberg, 2019, p.76). Readers engage with the piece by reading dream-like texts and moving through virtual spaces. Clicking on specific words redirects them to other texts/spaces. However, after visiting a text more than once, readers will notice that it has changed. It has become more coherent. Indeed, as described by Moulthrop, the author, "much of what you read on your first visit may seem like nonsense: in fact, it's generated by a set of simple random-assembly

programs. The text should become more coherent (if not more sensible) on repeated visits" (n.d., para 8). The programming of these successive changes helped Moulthrop explore "themes concerning the degeneration of memory within a virtual world" (Rettberg, 2019, p.76).

Illya Szilak applies the principles of hypertext in her novel 'Queerskins'. She based the main character, Sebastian, a young gay physician who dies from AIDS during the epidemic, on her experience as a doctor working in the United States during that same period. Adopting the point of view of someone who was both her and not her gave Szilak "the courage to write about extremely painful personal experiences and feelings" (Szilak, 2017, para. 8). In this sense, 'Queerskins' is both the story of Sebastian and Szilak.

After Sebastian's death, a box with his diary and other materials arrives at his mother's house. These documents are all that is left of him. To read 'Queerskins' is to navigate through these materials in the form of 34 chapters, each composed of images, diary entries, sound bites, and videos. In chapter 24, for example, the reader sees, on the screen, a page from Sebastian's diary dated 18 January 1989. Sebastian writes about the early days of the AIDS epidemic. "Once the epidemic began," he says, "there was so much confusion. No one knew how the disease was transmitted" (Szilak, chapter 24). Szilak is currently developing an immersive new version of 'Queerskins' using 3D volumetric video capture technology, 360° stereoscopic video, drone-assisted photogrammetry, and spatial sound (Szilak, 2020).

Hypertext works such as 'Patchwork Girl,' 'Reagan's Library,' and 'Queerskins' are medium-specific responses to enduring concerns in the study of illness narratives. The degenerative language in 'Reagan's Library', for example, offers a new form of literary experimentation concerning the communication of pain and suffering. In *The Language of Pain*, a book I discussed earlier, Biro sees metaphors as the key tools for developing a rhetoric of pain. A recurrent metaphoric construction, according to Biro, involves describing pain as an external force that attacks the person. In 'Reagan's Library,' dementia is brought forth not by metaphoric language or attack but by deterioration, as a coded process that makes meaning change on the screen. The non-linear navigation of the hypertext also offers a sense of disorientation to the reader.

'Queerskins' may be placed alongside literary efforts that since the 1980s have aimed to testify about the AIDs epidemic, a subject which I also referenced earlier. The outbreak of the disease was, at that time, quick to end the lives of many people and there was little explanation and hope. The materiality of the hypertext medium, fragmented and non-linear, sustains a reading experience and the feeling that there is more to be known and much that has been lost. 'Queerskins' is not a coherent first-person narrative. Instead, the reader is left with the task of

rearticulating Sebastian's life and illness by bringing together fragments of diaries and images.

There are also examples of game-like narratives (a different genre of electronic narrative) on the subject of illness. Game-like narratives rework aspects of "traditional fiction (such as character development, different models of temporal framing, and second-person point of view) to a ludic textual environment" (Rettberg, 2019, p.116). 14). Writers of interactive fiction also borrow elements from video game design, such as puzzle-solving, to advance a story. These are not "games to be won or lost, but worlds to be experienced, interacted with, and understood" (Rettberg, 2019, p.100).

'Depression Quest' is an interactive fiction game designed by Zoe Quin using Twine. In the game, players assume the role of a depressed person. They play by running through a series of mundane situations, including a house party, which they have reluctantly agreed to attend. At the party, players choose from a drop-down menu between options such as standing silently in a corner or drinking to alleviate the awkwardness. The environment also reacts to the player's emotional state: "audio and visuals react to your depression. Listen as the music gets glitchier and see how much stronger the static gets. Watch the color get sucked out of how you see the world" (Quin, n.d., para. 7). There are different possible endings to 'Depression Quest.' In some, "you start seeing a therapist, take your pills, stick out your job [...] In others, you slide further and further into despair, finding that each new screen contains fewer remaining option" (Lewis, 2014, p.341).

Today, Twine, the platform used in 'Depression Quest', is known for the experimental and, often, auto-biographical character of its games. In journalists Laura Hudson's words, "many of the most prominent Twine developers are women, making games whose purpose is to explore personal perspectives and issues of identity, sexuality and trauma that mainstream games rarely touch on" (Hudson, 2014, para. 4). 'Depression Quest', an example of this biographical games, is also known for being the game at the center of Gamergate. The event involved a group of (primarily male) gamers attacking female game's designers.

Illness is a formative component to 'That Dragon Cancer' by Ryan Green. The video game is about the death of Green's infant son, Joel, to brain cancer. Playing it means attending doctor's appointments, racing through hospital corridors, fighting monsters, and discovering a (virtual) world transformed by Joel's condition. Stylistically the game is highly abstract. In this way, it "is able to echo the bewildering, confounding experience of submitting to medical processes post-diagnosis, and then the devastation and numbness associated with having to come to terms with Joel's prognosis" (Schott, 2017, p.4).

The game also comments on the visibility of death in media and in video games in particular. In video games, death by violence is an acceptable form of entertainment. Death by illness, by contrast, proved to be shocking. 'That Dragon Cancer' foregrounds "a likely experience that players of the game will encounter either by losing someone close to them, or the end of their own existence" (Schott, 2017, p.2). While the game received praise, it was also the subject of controversy. Some people reacted by arguing that illness and the death of a child were inappropriate subjects for a game. Game journalist Andrew Todd reflects on this issue of appropriateness. When people raise the question to him, he simply asks them back, "would it be okay if a film did it?" Or, a book for that matter? (Todd, 2016, para. 12). Thinking of the many examples of illness literature and films that exist, the answer is simply: yes.

Games have medium-specific capacities to convey a sense of embodiment in relation to illness and grief. 'Depression Quest', as I described, materializes the decision fatigue associated with mental illness in a shrinking interface of menu options. It also offers a new manifestation to the metaphor of the journey/quest associated with illness narratives. Finally, embedded and coded in 'That Dragon Cancer' are metaphors about mortality and caretaking. The game only ends when one let's go and stops playing.

Networked literature, the last genre of electronic literature that I wish to address, is concerned with the material properties of digital and networked media, the culture that it sustains, and the forms of writing that it affords. For example, mobile phone novels are written for phone screens, a practice especially popular in Japan (Thompson, 2016), and text-message stories are told as a series of SMS messages (Wired Magazine, 2005). Writers have also used web homepages and social media such as Twitter to develop fictional narratives. A well-known Twitter novel is *Small Places* by Nicholas Belardes. It "follows one man's mundane day-to-day life, and his attempt to create philosophical meaning out of it" (Belardes, 2009, para. 1). It "was launched on April 25, 2008 at 9:38 p.m. with a cluster of tweets. By the time it ended on March 8, 2010 at around 30,000 words, the Twitter novel had gone viral across the globe" (Belardes, 2020, para.1). *Small Places* engaged with Twitter's affordances and culture: users documenting their day-to-day activities and updating others in real-time.

The topic of illness is present in *Deep Love* (Yoshi), one of the most successful mobile phone novels in Japan. The novel follows a teenage sex worker who contracts AIDs. It has been described as a "sordid, erotic, and hyper-violent autobiographical tales of rape, abortion, disease and other taboo topics (Erban, 2009, para. 1). While there are no other well-known examples of social media novels which take illness as plot, one can easily imagine an illness story written in the fashion of *Small Places*, the Twitter novel that I mentioned earlier. Overall,

the intersection of electronic literature and illness remains somewhat understudied. Its exploration warrants, perhaps, a book in itself.

Telling stories, however, not only matters to hardboiled literary online writing; it is also a major component of everyday social media usage. In the next pages, I attend to this non-literary form of illness online storytelling. These online illness stories rework issues of 'writing' about using digital media and pay attention to medium-specificity and platforms, as was the case in electronic literature. They also bring illness together with matters of audiences, dissemination, public-private narratives, and celebrity, which were already relevant in my review of mass media and illness.

A definition of networked selves and online stories

Storytelling and self-representation are ubiquitous online. Platforms such as Facebook, Twitter, Instagram, and YouTube are enabling people to document and share their lives in "unprecedented measure" (Page, 2012, p.i). People 'post' online about meaningful events such as a marriage or the death of a loved one. They also create content about their holidays, take pictures of their lunch, discuss politics, write about mundane troubles, and, indeed, discuss their illnesses.

To describe these storytelling subjects and their mediated identity performances, media scholar Zizi Papacharissi (2018) proposes the term 'networked self'. The networked self is engaged in forms of storytelling that sustain a sense of self, that is, that "help us make sense of the world surrounding us and find our place(s) in it" (Papacharissi, 2018, p.1). Telling stories is, then, about "using technology to help us make sense of who we are, who we have been, and who we can become" (Papacharissi, 2018, p.3)

The digital traces left by the 'networked self' represent an opportunity to observe patterns of "production and reception in a way that is less tractable for offline examples of face-to-face or written forms of narration" (Page, 2012, p.9). Researchers strive to use this online data to understand "how we tell stories in the contemporary networked digital environment" and to study "the sense of self attained (and imagined) via social media" (Papacharissi, 2018, p.1). Social-media acts of telling, Papacharissi also argues, "are restricted, enhanced, and adorned by the affordances of these platforms" (2018, p.4). The study of online stories, if one follows her reasoning, becomes necessarily intertwined with the study of platforms and "platform-sensitive research" (Bucher & Helmond, 2017).

Concepts for studying platforms have been debated, as I mentioned before, in relation to games and electronic literature (Montfort & Bogost 2009; Apperley & Parikka, 2015). These scholars call for technically informed analyses of software and hardware in gaming and storytelling consoles. New media studies, in contrast,

offers a more "inclusive and deeper iteration of platform studies" (Burgess & et al. 2016, p.2). New media researchers focus on "thinking critically about the best ways to understand the roles platforms play in mediating our media, communication and cultural environments" (Burgess & et al. 2016, p.2). Their goal is to integrate materialist approaches to the study of media with the "core concerns of the media and communication disciplines understood more broadly" (Burgess & et al. 2016, p.2).

In more detail, one can think about social media platforms such as Instagram and YouTube as technical infrastructures with affordances and algorithms. These affordances, in a narrow sense, are buttons for 'liking' and 'sharing,' templates for writing, and fixed character counts. It is through such set features and actions (e.g. 'sharing' and 'friending') that, for example, on Facebook, "friendships are programmatically organized and shaped" (Bucher, 2018, p.8). It through the same features and actions that we tell stories about our lives: we post, update, and comment.

Affordances are also, in a broader sense, the "kinds of communicative practices and habits enabled or constrained" by a given platform (Bucher & Helmond, 2017). For example, mobile phones afford portability, availability, locatability, and multimediality (Schrock, 2015). Availability, in turn, sustains a sense of 'always-on' connection, which could be beneficial when it comes to family and friends and less so in the work environment. The focus here is not only what the technology allows users to do, but also about how people make use of these technical features in different contexts.

Platforms, as I explain more in depth later when discussing digital methods, are also 'machines' with unique methods for logging-in and treating user-generated behavior and data. That is to say, the content we produce is ranked, recommended, placed in networks, and measured in terms of its impact. The 'treatment' of this content is a fundamental part of experiencing social media. Necessarily, platforms are, then, not to be approached as neutral conduits that simply transmit content. Rather, they are technologies, infrastructures, and environments with protocols, and cultures of use. They "traffic less in content, programs, and opinions than [in] organization, power, and calculation" (Peters, 2015, p.7).

With this platform sensitivity in mind, rigid definitions about what counts as a narrative are sidelined. Instead, scholars describe social media as having story-like qualities and narrative affordances, unique dimensions of temporality and authorship, and "able to inspire a narrative response" (Ryan, 2005, p.347). This sensitivity also calls for serious consideration of how storytelling emerges in relation to algorithms, design choices, and cultures of use. Below, I explore a number of propositions for how such storytelling develops.

An example: in her study of social media stories, Page (2012) describes prototypical narratives as linear, complete, and singled-authored. On social media, instead, she sees that "interaction appears in an episodic form, as sequences of messages that develop over time, and draw attention to the processes of storytelling, rather than focusing on a discrete narrative product" (Page, 2012, p.8). These characteristics are present in numerous online media, including blogs, which are important social medium for this book.

José van Dijck (2004) addresses blogs as online diaries and signals "how functions and features of the analogue and digital genre coexist and co-evolve" (para. 34). Diaries have been "typically thought to represent the record of an 'I' who constructs a view on him/herself in connection to the world at large" (van Dijck, 2004, para. 2). Blogs mirror, in this way, "the temporal form of a diary, their intimate focus on self-expression of experience" (McCosker, 2008, para. 9). However, they differ in that they have a reverse chronological order, are followed by readers, one update at the time, and exist as private-public documents.

Van Dijck situates the perceived paradox of private/publicness in historical context. Diaries, she argues, have always had an intended audience, be that an imagined reader, one's future self, or set community of readers. Online media reworks the notion of an intended audience. For example, "lifelogs later became experiments in self-expression, with people reading and cross-linking other lifelogs, thus creating blog-communities" (van Dijck, 2004, para. 12). The fact that blogs are written on a computer and not by hand, as was the case with diaries, does not compromise expressivity and personal touch. Instead, "through word choice, style, punctuation, and the use of emoticons it is remarkable how much the entries give away a person's character" (van Dijck, 2004, para. 21). Video vlogs which I study in Chapter 2 maintain and rework some of these characteristics.

The social media profile and timeline also conjure a sense of biography (Sorapure, 2015, p.271). For instance, the Facebook timeline brings together the updates created by the account owner "as a longitudinal narrative text" (Robards & Lincoln, 2017, p.1). One can aim to read it as the story of a person. Most frequently, Page (2012) concludes, these Facebook updates are open-ended and "interwoven with the participants' daily experiences, emphasize some kind of immediacy, and are highly embedded in their surrounding discourse" (Page, 2012, p.70). The Facebook timeline is, thus, composed mostly of 'small stories.' Taking this into account, one needs to consider "the extent to which a narrative can be detached from its surrounding rhetorical, discourse and social context" (Page, 2012, p.107).

Instagram, which is a visual social media app, has a different structure and affordances than Facebook. In his study *Streams of the Self*, Kris Fallon, a researcher of non-fiction visual culture, connects the Instagram account "with a traditional

notion of individual identity, temporal linearity and serial progression" (Fallon, 2014, p.58). Fallon suggests, for example, "that an account comprised exclusively of selfies literally works as a sort of timelapse progression of aging" (Fallon, 2014, p.58). It can also, as with the Facebook timeline, be read as a story of the self. In platform such as Instagram, also hashtags have acquired theoretical relevance. According to digital linguist Michelle Zappavigna (2108), one needs to approach hashtags both as metadata, that is, as devices that aid information discovery and the organization of content, and as semiotic devices that help make meaning and tell stories. In her argument, hashtags are a form of 'searchable talk' that people use to enhance the meaning of their online communications and connect with others. Consider, for example, a person who adds the hashtag #fitnessjourney ('fitness journey') to the selfie they took earlier at the gym. By doing so, they are embedding the image with meaning and "metacommentary" (Zappavigna, 2015, p.275). The coupling of image and hashtags communicates that the author is partaking in an effort (a journey) to become healthier. Also, adding the hashtag makes the post visible to other fitness enthusiasts who query Instagram for #fitnessjourney ('fitness journey'), leading to potential connections and thematic affinities. Tagging and the concept of 'searchable talk' in relation to illness storytelling are important in my study of tagged bodies in Chapter 3.

On sites such as Pinterest and Tumblr users tag content but also collect images, GIFs, and videos into personal mood boards. These media invite a different understanding of life writing. In media scholar Jill Walker Rettberg's words, while they "may consist of nothing but captioned reaction gifs, and expose nothing of the author's identity, yet [they] still express a personal experience of life" (Walker Rettberg, 2014, p.7). In this sense, "to really understand social media genres we need to see them as feeds and analyze each post or image as a part of a series" (Rettberg & Walker Rettberg, 20, p.33).

The practice of managing public personas has traditionally been the job of celebrities, and for them, the web has certainly opened a new myriad of channels to connect with their fans. Page (2012) analyzes tweets produced by celebrities. These tweets, she finds, are a medium for celebrities to tell stories both about their personal and professional lives. Their stories are also reworked by medium practices of "constructing intimacy, authenticity, and consumable identity" (Page, 2012 p.99).

Management of public personas is, however, now widespread beyond the already-famous. In fact, we all practice, in one way or another, 'micro-celebrity' and self-branding when publishing, curating, and managing our social media accounts (Senft 2008; Marwick, 2013; Abidin, 2015; Marwick, 2016; Mavroudis & Milne, 2016; Abidin & Brown, 2018). A part of micro-celebrity is to engage with both human and non-human audiences. That is to say, content about the self is created to be consumed by other social media users. These are the friends and strangers

(if the account is set to public) with whom we share selected documentation and stories about our lives. To ensure the visibility of the content they produce, people are strategic. For example, a person can include a hashtag (which is a topic maker) in their social media post, so that other people searching the platform may find it. In doing so, they are also making the content readable for the medium (hashtags are forms of metadata) in hopes that it will be placed in a content stream.

This capacity to make ourselves visible to others in strategic ways has been subject of much discussion. For example, communication scholar Stefanie Duguay (2018) is interested in queer women's micro-celebrity on Instagram. That queer women are adding hashtags to make their queerness evident and 'searchable,' intrigued Duguay. She asks: what does it "mean to them to include queer hashtags or other indicators of their sexual identity?" (Duguay, 2018, p.98). She views these "self-representations on Instagram— photos, videos, and the interactions surrounding them— as the building blocks for networked stories of the self that individuals shape and curate through platform affordances" (Duguay, 2018, p.94).

The stories we tell and our online/mediated self-representations are tailored with feedback from other platform users. The sense of self which is sustained online is thus "reflexively adjusted across platforms, publics, and taste cultures to enable optimal expression and connection" (Papacharissi, 2019, p. 2). Think, for example, of how people rarely present the same version of themselves across social media platforms. LinkedIn is for professional networking selves. On Instagram, people are more social and creative. Thus, "writing of the self into being" (boyd, 2007, p.) becomes an "ever-evolving cycle through which individual identity is presented, compared, adjusted, or defended against a constellation of social, cultural, economic, or political realities" (Papacharissi, 2013, p.207).

A separate topic of debate is the value of online storytelling. There is an impulse to dismiss the documentation and publishing of one's personal life as vain (Campbell, 2016). Papacharissi, through ideas of networked selves, and other researchers, instead, position blogging and social media postings in genealogy with traditions of diary-writing, self-portrait, and religious writing. They argue, for example, that, "as a quotidian habit, diary keeping gives meaning and structure to someone's life" (van Dijck, 2004, para. 7). These old and new practices of self-documentation have the potential for self-discovery and personal improvement (Walker Rettberg, 2014; Serfaty, 2004). In addition, scholars have theorized the "subcultural microcelebrity", "subversive microcelebrity", and "non-aligned micro-celebrities" by which online visibility is politicized (Fuller & Jeffrey, 2016; Raun, 2018; Badran, 2015).

Lastly, social media platforms, one needs not to forget, are services offered by for-profit media companies. The term 'social media platform' has evoked a rhetoric

of openness and participation (Gillespie, 2010). These are the spaces in which 'everyone' can have a voice, connect with others, tell their story, and, perhaps, become famous. Nevertheless, these claims to the democratization of visibility are nuanced by the commercial nature of platforms and their striving for popularity. Activity in platforms is, moreover, subject to 'terms and conditions' and data protection laws. According to these regulations, particular behaviors — hate speech, but also a post-mastectomy photo — can be deemed inappropriate. The content can be deleted and users' accounts blocked. Also, when considering 'users', here, one needs to include advertisers for which analytics afford marketing insights and researchers "who can collect and analyze platform data for studying social issues" (Light, Bugess & Duguay, 2016, p.4).

To sum up, social media stories are stories told by people on social media platforms. They are fragmented, present-oriented, networked, cumulative, and episodic, as well as related to self-representation and identity. Stories are told 'live' and made searchable through micro-celebrity practices. Thus, the 'networked self' is a storyteller, embedded in networks of stories. The infrastructures of these platforms shape storytelling in significant ways and platform sensitive research allows one to move between layers. Scholars interested in storytelling, thus, study profiles, content, and interfaces but also engages in critique that goes beyond representation 'as a surface effect.'

As I illustrate in the next section (which I call a short story of online illness stories), networked selves also use platform affordances to tell stories about illness, including stories about "being diagnosed and treated for terminal illness" (Page, 2012, p.2). All of these are "narratives of living, dying, and coming into being" (Papacharissi, 2018, p.1). Afterward, I will present my own typology of social media illness stories, which builds on and contributes to this cluster of existing work.

A Short History of Online Illness Stories

Early on, illness stories appeared in chatrooms and bulletin board systems. An example of the latter is documented in the book *@Heaven: The Life and Death of a Cyber Futurist* (Hastreiter, 2015). The year was 1994 and Tom Mandel, a Stanford futurist, had opened a discussion on a virtual community named The Whole Earth 'Lectronic Link (WELL). Mandel had a nasty cold and was using the 'conference' (or discussion board) to ask other members for advice about how to fight it. A few weeks into the conversation, it became clear that Mandel's illness was serious. In less than six months he was dead. Kim Hastreiter, a member of the WELL and editor of *@Heaven*, described the conference as a profound event. In his own words, "those of us who both lurked and exchanged support and love for Tom during this intense time morphed into a powerful little posse of accidental witnesses. Witnesses not only to his life and death drama but witnesses to the power of the Internet" (Hastreiter, 2015, p.11).

Three years after Mandel's death, medical journalist Faith McLellan wrote about a similar WELL conference. The conference's name was 'Leukemia' and it was hosted by a man writing about his son's cancer. McLellan described 'Leukemia' as an electronic narrative of illness. For her, the virtual meeting meant an "ongoing, unfinished text [which] may prove invaluable for teaching health-care professionals about patients' and families' experiences of illness" (McLellan, 1997, p.87). To study these, then new, narratives, she recommended "network analysis, content analysis, and participant observation" (McLellan, 1997, p.101).

Likewise, people have told illness stories using email and websites. According to McLellan (1988), "linkage, graphics, video, and audio possibilities" altered "the authorship, audience, form, and length of illness narratives" (p.40) She illustrated these points in her analysis of the website, 'Cancer Destroys, Cancer Builds'. The website was structured as "a photographic essay about a woman's experience of breast cancer" (1998, p.41). There was a text written by the patient under each photograph and visitors could access interviews between her and the photographer and send comments via email.

Another key text in the study of illness online is Shani Orgad's *Storytelling Online: Talking Breast Cancer on the Internet* (2005). As the title of the book indicates, Orgad studied the online storytelling practices of women with breast cancer. The storytelling activity occurs on websites, personal homepages, email, chatrooms, and blogs. Through these media, people share personal stories about diagnosis and treatment, post anecdotes, offer advice, and memorialize their experiences. Orgad argues that these activities are important for patients and intertwined with their 'real' lives and identities, instead, of being isolated from them. Moreover, storytelling develops in particular technological environments and is shaped by cultural dimensions such as genre, class, and nationality.

To capture these complex dynamics Orgad combines online observation, interviews with breast cancer patients, and the analysis of the websites where the narrating takes place. The invitation, here, is to consider what about the process of narrating illness online is particular and how do these particularities matter to women. Based on her study, Orgad demonstrates, for example, that dialogue and one-to-many communication co-exist and serve different functions. During difficult periods of the illness, women prefer asynchronous communication. These forms of communication permit 'slowing down'. In contrast, chatrooms demand an instantaneity that can be overwhelming. Active participation in forums also co-exists with 'lurking'. Having the option to be 'on' and then 'off' is appreciated by women with breast cancer. I reflect on micro-celebrity patients and their (in)capacity to disengaged from the medium in Chapter 2.

Orgad also touches on issues of web design and affordances in relation to process of narrating and self-representation. For example, on patient-oriented websites, creating personal profiles become a way for telling one's story through templates. A template, unlike an open form, involves filling out categories and choosing a set "a range of possible stories" (Orgad, 2005, p.150). In sum, Orgad teaches that to understand storytelling online one also needs to attend to media infrastructures in relation to people's unique experiences of illness, a point also relevant in my own work.

With time, media scholars began studying how patients use blogs and, later on, social media to tell stories and self-represent. This has involves looking at concepts from illness studies such as 'pathographies' (Hawkins, 1999) through the lens of online self-presentation, online visibility, and networked selves, which I introduced in the previous section. For example, Anthony McCosker and Raya Darcy define 'illness blogs' as blogs that "self-document the intimate and often intense experiences of living with serious illness" (2013a, p.1267). The 'work' performed by these bloggers is personal, network-enabling, and social. They demonstrate, for example, that blogs have become a tool for managing a disrupted life period, and create spaces for "shared traumatic experiences" and offer "networked help" (McCosker & Darcy, 2013, p.1268). This is also the case when people upload photographs of themselves "taking medication or suffering side effects" in an "effort to come to terms with diagnosis'" (Gonzalez-Polledo & Tarr, 2016, p. 1465). Based on this type of study, researchers argue that social media storytelling is helping patients recover a sense of agency.

McCosker and Darcy (2013), however, remark that "far from simply or magically empowering an individual, the self-expression of illness requires significant labor" (p.1273). They see illness blogging in relation to broader issues of digital labor that blur "modes of work, leisure, production and consumption" (McCosker & Darcy, 2013, p.1267). More pointedly, cancer bloggers are, in their view, involved in forms of immaterial and affective labor — that is, a type of "labor that produces an immaterial good, such as a service, knowledge, or communication" (Hardt, 1999, p.94). In exploring the manifestation of this immaterial labor, McCosker and Darcy found that the vast bulk of content was not dedicated to sharing technical health information. Rather, it "involved forms of self-expression and sharing that revolved around the personal, but also public management of often intensive, conflicted and tumultuous affects related to the impact of the illness on the body and everyday life of the author" (McCosker & Darcy, 2013b, p.1281).

McCosker and Darcy also studied the role of traditional media sources in cancer blogging. They found that these media approached cancer bloggers and asked for unpaid interviews and promotions. At the same, the blogger's online communications generate value for the platforms that host them. These conditions can make patients vulnerable to exploitation. The labor in relation to self-

representation is a subject of avid debate in media studies at large, with Abidin (2016a) discussing forms of self-promotion and "visibility labor", "aspirational labor" (Duffy, 2015), "digital labor" (Terranova, 2004), and influencing. These concepts of self-branding and aspirational labor will be important again to understand the activities of popular sick bodies, on Chapter 2.

To date, Carsten Stage's *Networked Cancer* (2017) is the most comprehensive study on the subject of cancer blogging. The book explores storytelling about cancer in the "era of networked self-expression, affective engagement, and measurement" (Stage, 2017, p.1). According to Stage, this current media environment has "significant consequences that affect how the narratives of illness are being produced, spread and received" (Stage, 2017, p.15). Existing work on illness stories, Stage argues, focuses too much on the therapeutic aspects of storytelling. He wants to focus on its entrepreneurial side. In accordance, he proposes a new type of illness narrative: the entrepreneurial cancer pathography. The concept builds directly on Hawking's previous work on pathographies, which I described earlier in this introduction.

With the term 'entrepreneurial', Stage is not referring only to an economic classification. Rather, the definition is open to different types of value-making, including the value derived from advancing social issues. Indeed, in online cancer stories the personal becomes "intertwined with the facilitation, financing and realization of personal, social and political projects" (Stage, 2017, p.10). The phenomenon has deeper connotations. Entrepreneurial cancer blogging challenges ideas about "how an ill person normally behaves and situates herself in 'the social'" (Stage, 2017, p.47).

Social media such as Twitter, Facebook, Instagram, Tumblr, and YouTube have generated their own wave of illness-storytelling research. Some of this scholarship adapts qualitative methods and concepts from illness literature to the web. For example, Allyson Jacobson (2018) uses ethnographic methods to study three YouTube channels run by women diagnosed with metastatic breast cancer. These channels, she argues, embody the three narratives styles proposed by Frank; the restitution, chaos, and quest narrative. In a similar manner, Tamar Tembeck (2016) proposes that the selfies taken by patients represent a new style of visual pathography. Like Stage, Tembeck also builds on Hawkins' work. Elena Gonzalez-Polledo (2016) describes how, on Tumblr, chronic pain patients create memes and visual metaphors about their experiences and annotate them with tags such as 'pain', 'chronic pain' and 'fibromyalgia'. Creating these images and making them public by way of tagging is important. This public content helps create networks of support and a multimodal vocabulary to speak about an experience often silenced. I return to these ideas of tagging and pain vocabularies in my study of tagged bodies, in Chapter 3.

The subject of illness — so I hope to have illustrated with this short history — has repeatedly been studied in media scholarship. Experts make a case for the importance of having a theory of the medium that connects with core societal concerns, including that of illness and pain. Indeed, as a media scholar, one's interest is not simply in media, "but in the ways in which the interaction between media and human beings gives a culture its character" (Postman, 2000, p.11). Accordingly, scholarship needs to reflect on "whether or not a medium contributes to or undermines humane concepts" (Postman, 2000, p.13). The work that I have reviewed, as I see it, interrogates, from different perspectives, our current media environments as lively spaces for the creation of cultures around illness, with the capacity to enhance or diminish the lives of people who are ill.

Online storytelling appears to be re-shaping the relationship of the sick person to others and themselves and expanding the horizon of what a sick person can be and do. Through online storytelling, patients are regaining agency over their life narratives and creating networks of help. However, digital labor and exploitation also emerge as issues in relation to online illness storytelling. My contribution to this area of research come forth as a typology of social media illness stories. This typology continues these lines of inquiry and builds on the existing scholarship and complements it by attending to the topic of the methods embedded in platforms and how they shape illness storytelling.

A Typology of Social Media Illness Stories

My understanding of illness and illness stories is informed by Frank (2013; 2019), Jurecic (2012), and Hawkins (1998), whose contributions I addressed earlier in this introduction. My work is also influenced by how Stage (2017), McCosker (2013), Page (2012), Walker Rettberg (2016), and Papacharissi (2017; 2019) approach storytelling online. Like some of these authors, I bring online stories together with existing illness theory and account for their networked, mobile, and 'social' characteristics.

On *Networked Cancer*, Stage builds, as said, on Hawkins' concept of the pathography and proposes a new type, the entrepreneurial pathography. This new pathography is about patients who maintain online audiences and generate income and awareness. This form of illness storytelling emerges from the attention economy of the web and blogging culture. By proposing this new type, Stage highlights certain aspects of a particular kind of storytelling practice online. Likewise, I offer types of social media illness stories. I have named mine stories of *popular, tagged,* and *ranked bodies.*

How I arrived at these concepts does differ slightly from the authors I have mentioned. In addition to affordances and cultures of use, I also make the methods already embedded in social media essential factors in my theorization

and analysis. Social media platforms are the socio-technical environments in which online storytelling takes place. They have affordances that shape behavior and possibilities for action. For example, users can post and read content, follow other users, and tag images. Platforms also support modes of knowing and participating that are 'always-on', attention-seeking, and mobile. Social media, I now would like now to emphasize, also have their own methods. They are, in this sense, machines that calculate, filter, rank, and create hierarchies. We see the outputs of these procedures as timelines and lists of recommended content. Platforms have different methods; this is also a way for thinking about their medium-specificity.

The social media machinery has intended applications— that is, what they are designed for—and also, people repurpose it for their own needs and goals. For example, Rogers calls Twitter an event-following machine because people use it to learn about the news and follow current events (2019, p.xi). Google is, according to Rogers, an "epistemological machine" that creates hierarchies of knowledge (2019, p.22). I am interested in how the methods embedded in platforms and the cultures of use that they support are part of illness storytelling online and how they open opportunities for research. These are the aspects that I emphasize in my typology, which I recapitulate below.

The first type consists of the stories of popular sick bodies, which I study on YouTube. Traditionally, to be 'popular' means to be liked or admired by many people. Also, it means that one is the recipient of attention and enjoys a solid level of social acceptance. YouTube is a space populated by vloggers and influencers who produce content about their lives and build audiences. Following Rogers' rationale, YouTube is a machine for micro-celebrity and "self-branding" (Hearn, 2010, p.427) and for gaining popularity and studying what is popular.

On YouTube, popularity is also the product of the methods of the medium. To gain and maintain popularity, vloggers (including those who are sick) employ techniques for audience engagement and "visibility labor" (Abidin, 2016) meant to ensure that people, in- and outside of YouTube, consume and interact with their content. YouTube also makes numerous aspects of the experience of popularity visible and calculable. A person can see how many 'up' and 'down' votes, comments, and views a video has. In turn, these metrics "shape the character of the most popular content" (Burgess & Green, 2009, p.35). That is, they become sources of knowledge about what 'works' and does not work on the platform, which can be put into practice. The metrics of popularity (e.g., numbers of views), in turn, help to determine how particular videos and channels are recommended and valued. People can "either deliberately attempt to produce content that will generate large-scale attention according to the present criteria, metrics, and algorithms, or they can ignore this altogether (and receive attention

from dramatically smaller audiences" (Burgess & Green, p.41). In sum, YouTube sustains an economy of popularity and "reputation" (Hearn, 2010, p. 421).

The stories of popular bodies are, accordingly, about people who vlog about their illnesses, engage in micro-celebrity, participate in economies of reputation, and become popular. The engagement that their vlogs generates is recorded and measured and opens opportunities for study and invites revisiting concepts from illness theory. How do patients speak about illness in ways compatible with medium-methods and formats of YouTube? How is vlogging and popularity shaping people's illness experiences and helping them become the tellers of their own story? Which aspects of the illness story resonate most with the audience? Being well-known on social media, as I demonstrate, also becomes part of the illness experience. It is something that patients discuss, just as the need to invest significant energy to maintain 'popularity,' which becomes an issue as the illness progresses.

The second type of illness story is about tagged bodies on Instagram. Instagram is a platform for publishing visual and textual content and, amongst other things, for building communities around issues and interests. These communities of interest depend, to a significant extend, on users tagging practices. For example, if one wants an Instagram post to be recommended or found via query, it is vital to add hashtags and keywords. Hashtags allow for the content to be indexed, noticed by others, recommended, and aggregated into thematic streams. Users of the platform experience these grouping affordances when clicking on a hashtag and, then, being re-directed to other posts which also included it and users who have similar interest.

Media scholars have studied the relevance of user-generated tagging practices, in and outside of Instagram. Tagging can be used to give visibility to stories and events, create groups, and coordinate action. For example, the term "hashtag publics" (Bruns & Burgess, 2015) describes the ad-hoc formation of people and ideas as facilitated by hashtags. This formation takes place, for example, after natural disasters and may help coordinate acts of generosity. Hashtags also enable forms of witnessing and "connective action" (Bennett & Segerberg 2012), as has recently occurred with the #metoo movement online. The moment is sustained, at least in part, by social media testimonies about sexual abuse annotated with hashtags, which are placed into networks by platforms.

The stories of tagged bodies are, thus, about patients who use tagging to give visibility to their (often disenfranchised) illnesses, reach others, and create publics. Arthur Frank, as well as other scholars, have remarked on the potential of public illness storytelling to help patients recover their voice and seek connections. I see on Instagram's machine-supported capacity to make oneself 'searchable' —that is by becoming a tagged body— an essential concern for the

study of illness storytelling online and of these goals. When and for whom does algorithmic enable visibility matter? Why is it relevant to be able to label oneself and not just to be labeled? Which publics and communities form around illnesses?

The third type of stories is about ranked sick bodies. To rank is to give entities a place in a grading system, usually communicated in the form of a list. According to media expert Ernest A. Hakanen, rankings are "value-organizing" tools (2002, p.246) that communicate quality and relevance. They become means for "knowing where 'one stands' or 'belongs'" in relation to others (Hakanen, 2002, p.246). Rankings are also crucial for how we access cultural content and organize social activities. Some rankings (and lists) like the New York Times' list of best-sellers are famous and hold a great deal of authority. I referenced this list earlier in this introduction when discussing *When Breath Becomes Air*, a biography about terminal cancer. The book was, according to the Times, a best-selling illness story. Amazon.com also presents lists of recommended books. The lists are not editorial (like the Times) but created by algorithms that use data such as a person's previous purchasing history. Algorithmic rankings like these "distill public sentiment into easily understood numbers and ratings, glossed as 'science', and work to build profitable reputation" (Hearn, 2010, p.428). Rankings, thus, circumscribe what and who we see online and shape decision-making, and therefore they have much to say about culture. While people are not in control of these ranking or, even, understand them, they participate in ranking cultures and their "reputation" economies (Davenport & Beck, 2002; Bueno, 2016).

Like popularity and tagging, ranking is also a topic of interest in cultural and media studies. For example, in her study of the politics of best-seller lists, Laura J. Miller (2000) discusses how "scholars have long relied on best-selling book lists to "indicate literary tastes or social trends for a given period" (p.286). Best-sellers lists, as Miller phrased it, are supposed to be an indication of what people are reading. However, when studying them it is important to take into consideration the economic context in which they are produced—who benefits from the list? Rankings also have normative effects and may act as self-fulling prophecies (Espeland & Sauder, 2007; Callon & Muniesa, 2007). Placing a book on a list of 'popular books' is likely to increase its popularity. Also, people tailor their behavior to match the measuring criteria. For example, search engine marketers tweak content so that it lands high on Google searches. People also devise clever means to go viral and trend.

The stories of ranked bodies that I study are illness stories that participate in the ranking cultures of platforms such as GoFundMe. On these platforms illness stories are placed on lists and assigned value, and are subject to ordering and evaluation. These stories are written with measuring criteria in mind and aspire to go viral. It is also through these ordered lists that people encounter illness stories online. These conditions invite seeing platforms such as GoFundMe as

mediators in people's illness stories. How are illness stories treated and evaluate by platforms and with what effects? How does ranking cultures of crowdfunding shape how stories are written? And which ones do better in the medium?

By proposing these concepts, I aim to describe particular aspects of illness storytelling online. These are not, of course, the only types of stories in the platforms I have chosen. In addition, in practice, as Frank phrased when discussing his own typology, types constantly interrupt each other. There are aspects of ranking that intersect with popularity and tagging is part of self-representing, too. That platforms handle stories, it is also worth clarifying, does not denote one-sided passivity. Popularity, tagging, and ranking is not something simply done to online stories by the methods of the medium. Illness storytellers engage actively with online devices and medium-methods, which they use strategically to achieve particular goals, such as gathering attention. Patients are media savvy and tell stories designed to do well in the search engines. Writing for the medium is also part of the story. In other words, in my work, I am interested in how sick people put the machinery of social media to work as well as how the machinery works on them, and how these dynamics may be repurposed for the cultural study of illness.

To accomplish these goals, I use digital methods as proposed by Richard Rogers. Digital methods are techniques native to online media and that build on and repurpose the methods embedded in social media platforms, which I have discussed here. In the next section, I define digital methods with more detail and situate them in relation to other frameworks for doing web research. Then, I return to the types of stories I propose and reiterate how I study them using digital methods in three concrete case studies.

Digital methods and social media as research machines

Digital methods represent a third moment in web research, marked by "a shift in the kinds of questions put to the study of the Internet" (Rogers, 2013, p.21). More precisely, digital methods are an alternative to earlier academic research that treated the web as a "virtual realm" apart (Rogers, 2013, p.20). Indeed, throughout most of the 1980s and 1990s the web was perceived as a frontier territory, a cyberspace, in need of discovery and building. Accordingly, virtual or cyber studies sought to understand the emerging and unique characteristics of virtual communities, online worlds, cyber communication, and netizens. This type of research was done exclusively *about* the web and online culture, perceived as being separate from people's 'real' lives. Doubts haunted the future of these cyber studies. Scholars wondered if "these cyber subcultures [were] worthy of attention or whether they are simply ephemeral, imagined communities, too fleeting, too superficial, and too 'virtual' to warrant serious exploration" (Thomsen, Straubhaar & Bolyard, 1998, p.2).

A turning point in web research (and a second moment) began with the "debunking" of the perception of the web as a virtual realm apart (Rogers, 2013, p.20). In place of this view, online activity started to be seen as complementary to people's lived experiences and framed by geography and culture. An important example of this new approach was proposed by ethnographers Daniel Miller and Don Slater (2000), who researched how inhabitants of Trinidad and Tobago used the Internet. Their study "challenged the idea of cyberspace as a realm apart where all 'inhabiting' it experienced its identity-transforming affordances, no matter their location [...] Trinis appropriated the medium, making it fit their own cultural practices" (Rogers, 2013, p.21). Likewise, there was interest in exploring tensions between the online and offline. For example, researchers have sought to determine if self-representation and disclosure strategies on the web corresponded to people's offline personas. For example, Back et al. (2010) found that Facebook profiles matched people's personalities rather than being self-idealizations. In these cases, the validity of findings made online depends on them being grounded using offline data.

Digital methods are not concerned with virtual worlds, cyber culture, and the habits of virtual residents. Neither are they preoccupied with the divide between real and virtual or with "how much of society and culture is online" (Rogers, 2013, p.21). Digital methods, instead, rework hardline distinctions between online and offline by making the Internet not only into an object of study but also into "a source" (Rogers, 2013, p.21). A better distinction is, then, between 'societal' and 'medium' research.

In societal research, researchers set to "diagnose cultural change and societal conditions by means of the Internet" (Rogers, 2013, p.21). Online media is a fundamental component of many social, political, and economic activities and, thus, a source of data about these activities. The researchers who study Facebook pages dedicated to politics during election season, for example, are not seeking to understand the dynamics of virtual communities. Instead, they employ Facebook as a source to understand contemporary politics. This is not research *about* the web as a realm apart. It is research about society *done with the web*. The critical question that digital methods pose is: what can be learned about society and culture from the data produced by web and social media platforms?

In medium research, researchers study media such as Google's or Amazon's search engines. They test, for example, if the algorithms that power these search engines exhibit biases. To do this, researchers set up experiments such as querying for the same products using different user-profiles and computers and seeing if the results change or prices are inflated. This type of investigation is also not about virtual phenomena but commercial monopoly by leading companies.

Digital methods (both as societal and medium research) opens the possibility of 'online groundedness' – that is, of considering "when and under what conditions may findings be grounded with web data? (Rogers, 2019, p.5) It is essential to clarify that the argument is not that research should *always* be grounded online or that digital methods should replace other forms of inquiry. Also, web data is not an appropriate source for answering all types of questions. The invitation made by the digital methods is to, instead, treat online media as a source of data about social and cultural life, when appropriate, and then to ensure the quality of the research, taking into consideration the specificity of the web.

Digital methods are, indeed, a form of medium-specific research: they use research techniques native to the web to study web data. This choice differentiates digital methods from other approaches for researching with the Internet. Virtual methods are, for example, different from digital methods. In virtual methods, one imports "standard methods from social sciences and the humanities into the medium" (Rogers, 2013, p.19). For instance, Thomsen, Straubhaar, and Bolyard (1998) agreed that the best way to study email chains was by using conversational analysis. Email, they argued, "can be conceptualized as "talk" among members and can be analyzed as such" (1998, p.9). Other examples are webometrics and alt-metrics, which are bibliometric techniques "for studying reputation or impact, applied to web data" (Rogers, 2019, p.9). Online surveys and virtual ethnography are also popular examples of imported techniques. In all these cases, the researcher is studying web data using digitized methods.

Another variation is to employ computational methods (which are also different from digital methods) in the analysis of digitized data "concerning language, art, music, literature, and media" (Centre for Digital Humanities, 2019, para. 2). For instance, researchers can use a scanner to digitize an extensive collection of novels. Scanning them will make the text 'searchable' and ready to be analyzed with the help of software. This software could help researchers identify patterns in the narration and relationships between characters, thus, semi-automating a form of literary analysis and doing "distant reading" (Moretti, 2015).

Another example, again, distinct from digital methods, is cultural analytics, the framework proposed by media scholar Lev Manovich (2012). Cultural analytics employs software to explore large collections of images ('big visual data') through their formal properties (e.g., tone and saturation). A person can use cultural analytics to unearth stylistic patterns in collections made of thousands of digitized magazine covers or hundreds of comic books (Manovich, 2012; 2015a; 2015b). In these cases, software for visual analysis generates insights that would not be possible with the naked human eye. In his project Selfie City, Manovich applied the same principle to studying thousands of selfies, downloaded from Instagram. He treats selfies as self-portraits, instead, of as networked objects, and sets to find similarities in how people pose and smile. While these "data science techniques

do not replace other art historical methods, they allow us to see familiar art-historical material in new ways, and also to study contemporary digital visual culture" (Manovich, 2015b, p.1).

As I have explained above, in virtual methods researchers adapt classic methods from the humanities and social sciences (e.g., ethnography) to study web data (interactions in chatrooms). Digital humanities apply computational techniques (e.g., distant reading) to digitized literature. In cultural analytics, software is used to automate visual analysis of image datasets (e.g., a thousand magazine covers). With digital methods, by contrast, one employs web data instead of digitized data and methods which are native to the web rather than imported into it.

In the previous section, I discussed the idea that social media have methods. These are what Rogers calls the 'methods of the medium'. These methods are how social media capture, format, organize, and process the digital traces left by online activity. Social media are, in this sense, machines that rank, tag, create networks with logged-in user behavior, and make lists. A list in this context can be the Facebook timeline, where users see the content their friends produce, organized according to relevance. Encoded in a platform's algorithms and programs are "the methods of the medium" (Rogers, 2019, p.36).

Digital methods repurpose the data and the methods already found in online media for societal and medium research, often with the aid of software tools. In other words, social media platforms become a "research machine" (Rogers, 2019, p. 129). Setting up a digital methods project begins with making sure that the platform and the phenomena that one wants to study are well aligned. The platform needs to be relevant for the actors and the topic in question (Venturini & et al., 2018). Afterward, the researcher inspects the machinery, so to speak, and learns how the platform formats activity, logs user-content, and creates data through activities such as posting, linking to, and commenting. Namely, one considers "what may be observed and learned from the traces left by users online" (Rogers, 2019, p.19). Next, the digital-methods researcher 'follows the medium' and pushes the epistemological readiness of these data and medium-methods and repurposes them into a series of steps for answering research questions.

Learning from the medium and following it are practical considerations for working with online media. For example, instead of lamenting that social media is popularity driven and not 'democratic' and then attempting to flatten the field, so to speak, one is better served by repurposing these already existing hierarchies. One may ask, for instance: which sources and voices are dominating a debate space? Similarly, digital methods shift the discussion about the 'dirtiness' of web data towards the need to minimize medium effects. More precisely, web and social media data are forms of residual data. The activity captured is not occurring in the 'wild' or controlled by the scientist. Instead, data are determined and collected

by commercial platforms. This data is what one calls "platform ready data" (Helmond, 2015). When using public or commercial web Application Programming Interfaces (APIs) or scrapping, likewise, one is subject to individual specifications. For example, Instagram made information available about posts, but the platform does not offer any demographic information about users. Thinking on these terms, helps researchers determine, from the outset, which types of research are better supported by a medium.

Researching with online media, as I mentioned above, also requires acknowledging, minimizing, and repurposing "medium effects" (Rogers, 2019, p.200). For example, links to Google 'properties' such as Google maps tend to be on the top of Google's results for any given query. When studying Google results, one may choose to ignore the links. Content in search engines and social media is personalized, instead of 'universal.' To minimize personalization, for example, researchers create a 'research browser' free of cookies and log out from Gmail before collecting data. Likewise, bots and 'hashtag piggybacking' that inflates popularity are almost always present in social media datasets. The second takes place when people (or bots) include popular yet unrelated hashtags in a post. Their goal is 'riding' a hashtag's trending moment. Researchers can account for this medium effect and make them part the analysis or acknowledge them and exclude from the findings.

I would like to further explain the processes of doing digital methods research with an example of a project that repurposes hashtags: 'For the People of Iran #iranelection RT' (Rogers et al. 2009). Hashtags are essential digital devices that help people direct attention to the content they produce and find content made by other users. The platforms, in addition, understand hashtags as indicative of trends, and recommends content to users through trendiness measures. They can be useful for the media scholar, who sees an opportunity to repurpose common hashtag use as well as platform calculations in the study of how topics are framed, and conversations structured.

'For the People of Iran #iranelection RT' centered around the street demonstrations that took place in Iran after the presidential elections of the summer of 2009. People based in Iran tweeted (albeit in limited numbers) to document and communicate what was happening there, using hashtags such as #iranelection. People elsewhere in the world used the hashtag to follow the event and voice their own opinions, and they retweeted significant tweets to continue spreading information and breaking the news. These online activities represented a source of data for those interested in studying what was occurring in Iran. Moreover, the hashtag, #iranelection, "became a means to follow the action, and also one to demarcate a set of tweets in order to study [...] the Iran election crisis both online and on the ground" (Rogers, 2013, p.5). The question that Rogers et

al. set to answer was: how can Twitter be made into a storytelling machine that recounts the events on the ground and on Twitter?

To answer this question, Rogers et al. created a tweet collection (of some 650,000 tweets) containing the hashtag #iranelection, produced between 10 and 30 June 2009. To use a single hashtag or combination of hashtags to create a database is a demarcation technique. Then, they used the available metadata of the tweet collection to identify the top three retweets per day and ordered them by retweet count. These retweets were then placed in chronological order, "as opposed to the reverse chronological order of Twitter and blogs more generally" (Rogers, 2013, p.5). The results were displayed on a screen in Twitter-like fashion. Overall, the project "tells the story of the day-to-day unfolding of the Iran election crisis as seen through Twitter. The top retweets show the urgency and emotion of those twenty days in June, when the tensions on the streets and the coverage in the media were at their height" (LIMA, 2009, para. 1).

I study the stories of popular, tagged, and ranked bodies using digital methods. For each of them, Instagram, YouTube, and GoFundme.com emerge as machines for illness storytelling calling for different research practices. In Chapter 2 – *Vlogging at the End of Life: Popular Bodies* – I study the vlogs of Sophia Gall and Daniel Toms. When one queries for 'cancer vlog' on YouTube, Sophia and Daniel's vlogs are in the top three results. On YouTube, users can organize the contents of a vlog and view them in different ways. The default setting is to see the newest video first and then move backward in time. The vlog can also be organized from old to new, that is, chronologically. Alternatively, it can be arranged to display videos organized from the most to the least popular. I study Sophia's and Daniel's vlogs through these filters, which are 'ways for seeing'. I called this technique a filtered-reading, with an emphasis on popularity. To facilitate my analysis, I employ the software tool "YouTube Tools", created by Reider (Reider, 2015). The device connects with YouTube's API and allows downloading metrics for channels, individual videos, and comments into a tab format. Here, my interest is with how illness and dying are told through vlogging and the particular conditions of being a popular patient.

First, I watched the vlogs in their entirety and performed a close reading of them in chronological order. While doing this, I paid particular attention to how Sophia and Daniel combined the vernaculars of lifestyle vlogging with illness storytelling. They both begin their stories in treatment, following a structure similar to what Arthur Franks, calls restitution narratives, which are stories about healing. At the same time, Sophia and Daniel are patients working to grow their audiences and becoming Internet famous. In this sense, the vlogs also resemble what Stage (2017) calls the entrepreneurial cancer pathography. Then, Sophia and Daniel worsened and transitioned into the end of life. Through these stages, they

recorded diaries from the hospital, took their audience along on their adventures, and hosted Q&A videos to generate engagement.

In the second 'reading', I revisit the vlogs, now re-organized according to popularity. I wanted to know which content attracted their audiences the most and also how posting and engagement fluctuated. As I illustrate in my analysis, for both Sophia and Daniel the most viewed video was the announcement that their health has worsened. Afterward, there are periods of inactivity that generate suspicion in viewers concerning the authenticity of the vloggers, which, in turn, compelled Sophia and Daniel to post response videos. These videos and their comment sections, which I analyze, became spaces in which both patients and viewers discuss the particularities of popularity and of vlogging at the end of life.

In Chapter 3, *Tagged Bodie and Wounded Healers,* I study how Instagram users produce and tag content about stillbirth. This public storytelling is meaningful, as stillbirth is typically not discussed publicly and carries a stigma. To understand the networked storytelling and publics that form through their social media activity, I collected data using the Instagram 'Visual Tagnet Explorer' and repurpose hashtag practices to conduct social analysis. With the tool, I assembled a collection of about 7000 posts that contained the hashtag #stillbirth and visualized the data as a co-hashtag network. In co-hashtag networks, nodes are hashtags. Edges indicate that they are used together in a post. I ask: what do hashtags as devices afford bereaved mothers? My analysis of this network and the content comes about as an iterative process of close and distant reading of Instagram posts and hashtag practices informed by cultural studies about stillbirth, illness theory, and 'hashtag theory' (Zappavigna, 2018). As the research comes to illustrate, hashtag-work is vital for practicing "wounded healing," that is, Frank's concept for how storytelling may become a way for being for the other. On Instagram this develops from the capacity to tag personal grief and hope and thus make it visible, ambient, and networked.

In the fourth chapter, *Crowdfunding and the Ranked Body,* I study medical crowdfunding on GoFundMe. First, I analyze the advice GoFundMe gives its users for how to tell 'good' illness stories. Second, I conduct what Rogers calls the "biography of a website" to outline changes in GoFundMe's ranking practices (Rogers, 2019, p.87). This type of digital methods work repurposes The Internet Archive's Wayback Machine, which is a service that allows people to visit archived versions of websites, to trace the evolution of the domain gofundme.com and its rankings over the past ten years. Based on this, I propose a periodization based on liveness, sociality and trending.

I decided to work with digital methods for several reasons. Digital methods allow engaging directly with the methods of the medium, which are a crucial component in my typology of illness stories. In addition, digital methods are designed to work

with objects of studies (social media) that are constantly changing. Features in platforms are re-designed, buttons are removed, and the ranking criteria are tweaked. To ensure research practicality, I found it important to work closely with the medium and to use tools and research techniques that build on top of the platforms that I study. There are, of course, challenges and limitations to the scope of my work. First, I have focused on western and English spoken media. Thus, cultural differences —for example, how the subject of stillbirth would be discussed in non-western contexts—escape the scope of the work. On the importance of taking such differences into account, see, among others, Gentz and Kramer, (2012). There are also questions inspired by the case studies that would need to be answered in combination with other methods.

While working on these case studies, I also have also taken appropriate ethical considerations. All the case studies involve communications on social media which are public and meant for broad (or semi-broad) audiences. In other words, I did not join any closed patient groups. I also favored storytellers who sought attention or had as a goal raising awareness and 'breaking the silence.' Only the first chapter on YouTube vlogging zooms in on individual social media users. In terms of privacy, I felt comfortable with the research, in view of Sophia's and Daniel's status as online 'celebrities' and the size of their audiences. When referencing comments left under their videos, I did choose not to include YouTube handles of the authors. In addition, I submitted the case study to be reviewed by the Amsterdam University Hospital Ethics Research Committee, which provided authorization.

For the second and third chapter, I also ensured ethical research design. The second chapter works with Instagram data. The data was obtained through the Instagram API as of 2017 and thus followed the data capture regulations enforced by Instagram at the time. In my analysis, I zoomed in on networks of hashtags rather than on personal accounts. When using examples from the dataset to illustrate my argument, I paraphrased them and omitted the name of the authors. I also 'obscured' the few images included in this second chapter. By obscuring them, I mean that I have edited them digitally by elevating the contrast. As a result, one only sees silhouettes. This technique is employed in similar work by authors such as Tiidenberg and Baym (2017) and Cesare and Branstad (2017). It involves 'fabrication', a practical method for handling data "involving creative, bricolage-style transfiguration of original data into composite accounts or representational interactions" (Markham, 2012, p.334). The third chapter is a critique of GoFundMe.com and does not center on personal stories or reveals any sensitive personal data. The archived version of the website was obtained through the Internet Archive and The Wayback Machine.

A final note on ethics. In the three case studies, I have embraced what Jurecic has called a hermeneutic of listening. To the best of my ability, I have acted

respectfully towards the people and the stories that I have written about and have spoken publicly on different occasions. Most importantly, I have allowed myself to be moved by these stories and to learn from them. What I have learned is, then, what I attempt to share with my readers in the chapters that follow.

A Rising Digital Health Humanities Agenda

The last point I would like to raise in this introduction pertains to the researchers who have posed the question: what might constitute a digital agenda in the health humanities? The main focus of their inquiries has been on digital health, which includes the design and use of technologies in healthcare such as medical imaging technology, mobile biosensors, fitness trackers, medical apps, and dedicated patient-networking sites. Expert concern is with how these digital devices are transforming human experiences of health and illness (Ostherr, 2017).

Existing literature on the subject remarks the need to consider 'platform politics' in relation to digital health – that is, considering how, in digital health technologies, the wellbeing of patients is managed in relation to commercial interests. There is also a call to explore how technology impacts the relationship between health practitioners and patients, specifically, when automation plays a role. In exploring this issue, researchers draw from media studies, STS, and design.

For example, in *Medical Visions* (2013) Kirsten Ostherr explores the cultural life of medical images "in our mobile, image-saturated, digitally connected society" (p.14-15). Medical images range from the scans produced by MRI machines to the data visualizations made with Fitbit users' biometric data. The study of these medical images requires bridging "humanistic and biomedical concepts of visual evidence" (Ostherr, 2013, p.7), in order to, for example, understand "how doctors and patients are mutually constituted through mediated looking relationships" (Ostherr, 2013, p.7). Similarly, in *The Transparent Body* (2005), José van Dijck explores how "medical and media technologies converge on the production of visual spectacle —displaying the inside of the human body" (p.10).

About MRIs, Ostherr writes: "does this revenue-generating electronic eye operate as an extension of the gaze of the physician, who after all provides the essential interpretation of the data for the patients? Or has the physician become in some sense subverting to the imagining technology itself, occupying a middle ground between the patient and the robot?" (Ostherr, 2013, p.5). Ostherr also sees an urgent need to engage critically with AI, as an evolving technology in healthcare. Consider, for example, AI that can help make a diagnosis. Here, one needs to explore if the computerized diagnosis is taken as second opinion by the practitioner or if, instead, it is deemed to be more authoritative. Questions as the aforementioned are relevant, for example, for the training of doctors in the use of

digital technology, and for reflection on "the opportunities created by the Internet and new technologies to improve the doctor-patient relationship" ("Digital Health Humanities", 2020, para. 2.).

In this interrogation of AI-powered digital health, the subject of illness narratives emerges with respect to natural language processing, which could help find patterns amongst doctors' notes and illness stories. Ostherr raises the question: "could NLP be marshalled by health humanists as a mechanism for restoring the patient's voice to the center of the healthcare experience or is it a step too far toward automation of human narratives of illness and caring?" (Ostherr, 2019, p.12) Concerns regarding AI that require humanties perspectives also include data privacy and security, informed consent, risk and liability, professional expertise and training, explainability of results, flawed, biased, or incomplete datasets (Ostherr, 2019, p.1).

In her study of health apps, Lupton combines sociological approaches with media studies and science and technology studies (Lupton, 2012b; Lupton, 2014a; Lupton, 2014b; Lupton & Jutel, 2015). She describes health apps and self-tracking software as technologies to "capture and materialize immanent dimensions of human embodiment, creating human–data assemblages" (Lupton, 2018a, p1). The key to studying these 'lively assemblages', she argues, is learning to interpret how data become participants in people's lives. For example, Lupton asks: "what aspects of bodies/selves are left out altogether in digitized practices and knowledges?" (2018a, p.6) Similarly, Van Dijck and Poell (2016) critiqued how health apps present themselves as tools for personal and public 'good,' while obscuring issues of data protection and ownership.

Olivia Banner (2017) is concerned with the 'voice of the patient' as part of the conditions of extraction and value-making of 'bio-communicative capitalism.' The digital traces left by patients who communicate online, for example, in patient networking sites, are key for the industry of digital health. Thus, Banner invites reflection about how one can conciliate profit-driven communication technologies with an idealistic notion of voice and agency. As Banner and other authors whom I reviewed see it, a patient's communications and self-tracking generate value but also serve as free labor. Banner critiques, for instance, the data capture strategy of the patient networking site Patients Like Us. The affordances of the site, she argues, determine what data is captured and how it is presented to users. At the moment, she concludes that the interface is biased against experiences that fall outside of medicalized western discourse. For example, the template is blind to health-related questions that are relevant to native Americans in the United States. The rigidity of interface may lead to these patients becoming excluded. It also shapes the datasets produced and the knowledge they will come to inform. In these web assemblages, Lupton also argues, search engines and algorithms are

"influential actors in shaping the ways in which health and medical information is presented and delivered" (Lupton, 2018b, p.284).

My work on social media echoes the concerns expressed by Ostherr and Banner and brings them to mainstream social media. My analyses also expand their work: I propose that attention to social-media illness stories and medium-methods contributes an additional perspective in the health humanities. I address illness stories precisely in connection with medium-methods and platform cultures. By comparing and discerning between popular, metadata, and ranked illness stories, I will consider the issues of voice and community as part of and in conflict with the logic of media algorithms' visibility and edited selves. To this broader reflection I return in the concluding chapter of this book.