Illness online
Popular, tagged, and ranked bodies
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ILLNESS ONLINE

POPULAR, TAGGED & RANKED BODIES
Illness Online. Popular, Tagged, and Ranked Bodies

ACADEMISCH PROEFSCHRIFT

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aan de Universiteit van Amsterdam
op gezag van de Rector Magnificus
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# Table of contents

**ACKNOWLEDGEMENTS** .......................................................................................... 5  
**LIST OF FIGURES** ............................................................................................. 6  
**LIST OF TABLES** ............................................................................................... 7  
**CHAPTER 1 INTRODUCTION: SOCIAL MEDIA ILLNESS STORIES** .............. 8  
**STUDYING ILLNESS AS A HUMANITIES SCHOLAR** ........................................ 13  
  *Illness and stories* ............................................................................................... 13  
  *Illness and Narrative Studies* ........................................................................... 16  
**NARRATIVE TYPES AS LISTENING DEVICES** .................................................. 20  
  *Applied Narrative and Other Interventions* .................................................... 24  
  *Other Perspectives* ......................................................................................... 25  
**STUDYING ILLNESS AS A MEDIA SCHOLAR** .................................................. 29  
  *Mass Media and the Representation of Illness* ................................................. 29  
  *Electronic Literature and illness* .................................................................... 33  
  *A definition of networked selves and online stories* ..................................... 38  
  *A Short History of Online Illness Stories* ..................................................... 43  
  *A Typology of Social Media Illness Stories* ................................................... 47  
  *Digital methods and social media as research machines* ............................. 51  
**A RISING DIGITAL HEALTH HUMANITIES AGENDA** ................................ 59  
**CHAPTER 2 POPULAR BODIES: VLOGGING AT THE END OF LIFE** .......... 62  
**SICK MICROCELEBRITIES** ............................................................................... 63  
**To Study Popular Bodies, Adjust the Filter Twice** ........................................ 70  
**READING 1: BECOMING TERMINALLY ILL IN FRONT OF AN AUDIENCE** .... 71  
**READING 2: LOW PRODUCTIVITY, DEATH, AND A CONCERNED AUDIENCE** 76  
**THE DIFFICULTIES OF POPULAR BODIES** .................................................. 80  
**CHAPTER 3 TAGGED BODIES AND WOUNDED HEALERS** ......................... 84  
**TAGGING PAIN AND LOSS** ............................................................................. 88  
**HASHTAG THEORY: WHAT DO HASHTAGS DO?** ......................................... 91  
**CO-HASHTAG NETWORK ANALYSIS** ............................................................. 92  
**USING HASHTAG CAMPAIGNS TO MAKE #GRIEF AMBIENT** ..................... 97  
**LOSS AS A #JOURNEY** .................................................................................... 102  
**REACHING BEREAVED #MOTHERS THROUGH PROMOTIONAL HASHTAGS** 106  
**TAGGED BODIES, WOUNDED HEALERS, AND LIFESPANS** ....................... 109  
**CHAPTER 4 CROWDFUNDING AND THE RANKED BODY** ......................... 112  
**GoFundMe’s Plots and Advice for Telling Stories** ........................................ 115  
**Studying GoFundMe’s Rankings through a Website Biography** .................. 122  
**Ranking Campaigns According to Freshness, Sociality, and Trending** ........ 126  
**Ranked Bodies, Deservingness, and Calculated Spaces of Care** ............... 132  
**CHAPTER 5 CONCLUSIONS: ALGORITHMIC VISIBILITY, EDITED SELVES, AND LIVENESS** .............................................................................................. 134  
**Case Studies and Lessons about Illness Online** ............................................ 139  
**Contributing to a Digital Agenda in the Health Humanities** ...................... 144  
**SUMMARY** ....................................................................................................... 146  
**SAMENVATTING** ............................................................................................ 149  

- 3 -
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Amsterdam 2020
List of figures

Figure 1: Sophia’s vlog 74
Figure 2: Daniel’s vlog 75
Figure 3: #stillbirth co-hashtag network 94
Figure 4: Capture your grief 2017 99
Figure 5: Motherhood in loss 100
Figure 6: Hope and pregnancy loss 103
Figure 7: Meme encouraging women to speak up 104
Figure 8: Motherhood after loss 105
Figure 9: Pregnancy after loss selfie 106
Figure 10: Mama bear T-shirt 107
Figure 11: Angel baby figurine 108
Figure 12: Why crowdfund for medical expenses? 118
Figure 13: Tell your story 119
Figure 14: Help by sharing 121
Figure 15: A campaign’s public metrics 122
Figure 16: www.gofundme.com in the Wayback Machine 126
Figure 17: Ranking donations according to ‘liveness’ 127
Figure 18: Recent donations 127
Figure 19: Ranking campaigns according to sociality 128
Figure 20: Trending in medical crowdfunding in 2018 131
**List of tables**

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table 1</td>
<td>Comments on Sophia’s and Daniel’s videos.</td>
<td>74</td>
</tr>
<tr>
<td>Table 2</td>
<td>Clusters with examples of hashtags.</td>
<td>92</td>
</tr>
</tbody>
</table>
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

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 Brilliant 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. Ricoeur 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).

Underlying 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 person’s 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). 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 a 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 programatically 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 multimediiality (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 single-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 (2018), 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 repeatably 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-fulfilling 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
respectedly 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 humanities 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/soles 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.
Chapter 2 Popular Bodies: Vlogging at the End of Life
Sophia Gall was an Australian teenager active on YouTube from December 2015 to February 2018. Her channel had more than 150,000 followers and 8,000,000 views. Daniel Toms, a British man in his thirties, vlogged from September 2016 to September 2018. His channel had about 152,000 followers and more than 5,000,000 views. Both Daniel and Sophia vlogged about life with cancer, announced to their viewers that their conditions had become incurable, and, later on, documented their transition into the end of life. If one queries YouTube using the term ‘cancer vlog’ and organizes the results according to ‘view count,’ both Sophia and Daniel are among the top results. Their illness stories are examples of what I call stories of popular bodies.

In this chapter, I present the results of an investigation into how Sophia and Daniel disclosed intimate aspects of their illnesses using the format of lifestyle vlogging, which involves microcelebrity, entrepreneurialism, and self-commodification. Sophia combined, for instance, diary-style videos about her treatment with makeup tutorials and content about travelling the world with her family. Likewise, Daniel posted about his condition, created educational content for his audience, and sold merchandise with the slogan of his online campaign, #DontGiveInDontGiveUp.

Sophia and Daniel succeeded at engaging online audiences, who faithfully watched and commented on their videos. This online popularity came to shape Sophia’s and Daniel’s experiences and illness stories. They received support and validation from their viewers and accomplished personal and professional milestones such as meeting celebrities, raising awareness, and receiving an award for their role as health influencer. However, as the results of the analysis also show, online popularity is costly for illness storytellers, who find themselves scrutinized minutely by their viewers. Specifically, I discuss how viewers reacted to the vloggers’ disclosure of the incurable status of their diseases, a peak in terms of audience engagement for both vlogs. I further cover the difficulties that followed as their health deteriorated and they were unable to maintain the rhythm of online publication.

Sick Microcelebrities

Despite advances in treatment options, a large majority of patients diagnosed with cancer ultimately have to face the premature ending of their life. Under these circumstances, people are confronted with the challenge of re-articulating their personal experiences and identities in ways that accommodate a changed reality and help them create meaning at the end of life (Romanoff & Thompson, 2006, p.301). For many individuals, this requires a revision of the assumptions that

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1 The numbers were recorded on 3 February 2020
2 The query was performed on 3 July 2018.
have ordered and guided experience and requires the construction of a new life story” (Romanoff & Thompson, 2006, p.309). These assumptions range from mundane practicalities, emotional well-being, and questions of identity to existential concerns about “the meaning of life and death” (Bonanno & Kaltman, 1999, p.769).

Outside of medical contexts, we encounter ‘end of life’ stories in nonfiction and fictional popular media. Often, these stories explore the unique perspective of people who are facing death and their search for meaning. For example, in the book When Breath Becomes Air, which I referenced earlier in my introduction chapter, Paul Kalanithi, a neurosurgeon with an inoperable brain tumor, reflects on how he would like to spend his time. If he knew he had a year to live, Kalanithi said, he would pursue writing. However, “give me ten years. I’d get back to treating diseases” (2016, p.162). Another example is the book Five Regrets of Dying (2012), authored by palliative care nurse Bronnie Ware, who spent several years recording the “dying epiphanies [of her patients] in a blog called ‘Inspiration and Chai’” (Steiner, 2012, para. 2), which later was published as a book. Ware wrote about “the phenomenal clarity of vision that people gain at the end of their lives, and how we might learn from their wisdom” (Steiner, 2012, para. 3). These experiences, she considered, had to be shared with the public.

Fictional accounts about young people who suffer from life-threatening conditions have become a popular movie genre, too. A recent example is Five Feet Apart (2019), which follows the love story of two teenagers with cystic fibrosis, a condition that leads to a buildup of fluid in the lungs. To prevent cross-infection, “people with CF must not come within six feet of each other, hence the title: when these two falls in love, they decide to steal back a foot’s worth of intimacy” (Rose, 2019, para. 2).

The stories of Sophia Gall and Daniel Toms are non-fictional accounts about illness and the end of life. However, unlike the books and movies I have referenced above, they were told ‘live’ on YouTube through the formats of lifestyle vlogging. Broadly speaking, vlogging stands for video blogging. It is “a remediation of blogging (itself a remediation of the diary) [which] grew out of the user-generated content and prosumerism phenomenon and now represents an important subset of YouTube as a whole” (Arthurs Drakopoulou & Gandini, 2018, p.9). As a form of online publishing, it is, in principle, available to “everyone with web access and simple video production tools – such as a computer and a webcam or a cell phone with video capabilities” (Molyneaux et al., 2008, p.2).

On YouTube, vlogs are organized as a series of videos which users have uploaded onto their personal channels. On a channel’s page, the default is for the videos to be displayed from newer to older, even though there is the option to rearrange them from older to newer or according to popularity. The latter is an indication
of the quantity of views, upvotes, and comments a video has received. There are different types of vlogs. In review and unboxing vlogs, for example, YouTubers offer informative reviews. The ritual of ‘unboxing’ consists of a vlogger’s first-person point of view as they explore a product. There are also vlogs dedicated to pranks, fitness training, beauty, travel, celebrity gossip, film critique and —the genre on which I zoom in here— lifestyle.

Lifestyle vlogs are based on a vlogger’s life, interests, and skills. They include diary-style or confessional videos in which people share intimate details about their lives. Commonly, they are videos in which the vloggers introduce their friends and family, as well as videos with ‘facts about me’ and about ‘a day in my life’. To make the latter, you need to “start recording when you wake up in the morning and take viewers through a typical day in your routine” ("YouTube Video Ideas", 2019, para. 9).

Olivia Jade Giannulli is an example of a popular lifestyle vlogger. The daughter of Hollywood actress Lori Loughlin and designer Massimo Giannulli, Olivia Jade describes her channel as being composed of “videos talking about makeup, fashion, lifestyle, and occasionally [...] challenges” (Olive Jade, n.d.). Her channel includes, for example, a video titled ‘Olivia Jade - Everyday Routine.’ In the video, she walks her viewers through each step of her makeup routine. The post has about 1.3 million views. Olivia Jade has also posted videos about her last day of high school, getting ready for college parties, and travelling to Europe with her sister.

The YouTuber is also infamous for her role in the so-called Varsity Blue’s scandal. The scandal revolved around criminal attempts to influence undergraduate admissions decisions at top American universities. According to a report in Vanity Fair, Olivia Jade’s parents “face federal bribery charges in connection to paying $500,000 paid via a university whisperer’s slush fund in exchange for getting Olivia and her sister, Bella, into USC through the athletic program” (Bryant, 2019, para. 2). After a taking a break of about 6 months from her channel due to the scandal, Olivia Jade returned on December 2019.

Olivia Jade’s vlog (and lifestyle vlogging, more generally) is an expression of what Theresa Senft (2008) coined ‘microcelebrity.’ The term first described the then-new activities of cam-girls and early users of Live Journal and Facebook. These spaces were hosts for innovative experiments in self-representation that balanced authenticity, branding, and publicity (Senft, 2008; Khamis 2017, p.203). Now, more than a decade later, microcelebrity is best described as a widespread practice of self-representation and visibility management on social media (Senft, 2013). In other words, most social media users regularly produce and curate content about

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3 9 February 2020
their lives to command attention within networks of followers. While it is true that the practice is widespread, it is also true that some microcelebrities, such as Olivia Jade, are particularly successful at commanding attention in YouTube “reputation economy”. These social media users are called ‘influencers.’

Olivia Jade is also an example of mainstream microcelebrity, as she fits conventional beauty standards, shares snippets of her fun-filled life, and showcases luxury, attainable to her through her parent’s wealth but aspirational to many people. Other lifestyle vloggers, in contrast, are what Raun (2018) calls “subcultural microcelebrities.” An example is Julie Van Vu, who Raun describes as the most famous YouTube vlogger of 2018 in the genre of “transgender video blogging” (Raun, 2018, p.99). Julie’s ‘About’ section describes her as a “transgender woman who has a passion for makeup artistry and fashion. She is mainly known for sharing her transition and life experiences authentically on YouTube in hopes to educate and change people’s perspective on transgender people” (PrincessJoules, n.d.).

Van Vu’s channel includes videos of her unboxing beauty products, videos about her transition, diaries about her travels, a video called “My dad finally accepts me?”, and another one titled, “Transgender Moustache & Downstairs Laser Removal!” According to Raun, Julie Van Vu stands out because of how she combines the political aims of transgender vlogging with “sponsored/commercially driven tips and tricks on make-up, beauty and body modification” (Raun, 2018, p.103).

Lifestyle vlogs are personality-driven and depend on “visibility labor” (Abidin, 2016) and the performance of authenticity and intimacy. Visibility labor “is the work individuals do when they self-posture and curate their self-presentations so as to be noticeable and positively prominent among” their audiences and followers (Abidin, 2016, p.89). These qualities result from the ways vloggers speak, edit their videos, create a mise-en-scène, and share information. Vloggers tend to speak in the plural ‘you’, for instance, and they include dietetic references to time (e.g. today and now) and space (here, this) (Tolson, 2010, p.280). Vloggers engage with their viewers by asking them to comment on their videos or to provide recommendations. In doing this, vlogging adopts a style similar to ‘broadcast talk,’ which mimics familiarity and co-presence (Tolson, 2010, p.278). There is also an expectation for vloggers to actively promote and grow their channels and, thus treat authenticity and intimacy as commodities. In Alice Marwick’s words, “while mainstream celebrities are expected to protect their privacy, micro-celebrities cannot or they’ll lose this attention” (Marwick, 2013, p.143).

Furthermore, lifestyle vloggers are expected to present different facets of their personalities and lives. The perception of authenticity and intimacy, one may argue, depends on a balanced performance between a “frontstage, official self to a
more middle-region self with some sort of exposure of the individual’s life and emotions to a more backstage self, motivated by ‘temporary emotion’ (Raun, 2018, p.106). Julie Van Vu’s vlog neatly illustrates this need: on her channel, polished videos about fashion (a frontstage self) co-exist with her more raw discussions about sexual trauma (middle self) and with less planned responses to events in her life, which can be interpreted as glimpses of a backstage self.

Audiences have questioned the authenticity of television personalities and broadcast talk, thus engaging in a form of hermeneutics of suspicion (Scannell, 2011), a term I introduced earlier also in relation to both Jurecic (2012) and Ricouer (1970). An audience may wonder if the friendly demeanor of a talk show host is real, or if it’s just for the cameras? Lifestyle vlogging is also met with suspicion. For example, the format is critiqued for being a form of “aspirational production” of the self (Marwick, 2015, para. 58) and “success theatre” (Wortham, 2012, para. 5), which is the exclusive presentation of people’s frontstage selves. Here, viewers wonder, is the vloggers’ life as fabulous as it looks? Or has the self been edited to the point of no recognition?

Authenticity is, in fact, actively policed by online viewers. It is not unusual to read about influencers who are accused of being ‘fake.’ A highly publicized example involved makeup artist and YouTuber James Charles, who was accused by fellow beauty vlogger, Tati Westbrook, of foul play. In a fifteen-minute long video, “Ms. Westbrook [...] described in detail how an Instagram ad that Mr. Charles posted on behalf of a rival supplement’s company was a betrayal of their friendship” (Safronova, 2019, para. 4). The message was: James Charles is not as sweet as he seems. As a result of the accusations, he lost about three million followers on YouTube and was subjected to abusive comments. For Julie Van Vu, commercial collaborations are, in themselves, a grey area since she believes they could compromise her standing with the transgender community.

Like Olivia Jade Giannulli and Julie Van Vu, Sophia and Daniel are popular lifestyle vloggers and microcelebrities. They published content about their lives and illnesses through performative strategies, including those of intimacy and authenticity. They planned and edited their videos and created parasocial relationships with their viewers. The content they produced was diverse and showcased different aspects of their lives, as is typical of lifestyle vloggers. In addition, Sophia and Daniel explicitly worked towards growing their audiences.

These aspects differentiate lifestyle vlogging about illness not only from other more established formats of illness storytelling like autobiographies, but also from other formats for illness storytelling that are performative in nature. Tembeck (2009) studied such “performative autopathographies” (p.1) in theater, self-portrait, performance art, choreography, and the selfie movement, #HospitalGlam. The authors of these pathographies are patients whose
performance techniques have “less to do with conveying the immediacy of experience [...] than with the transformative role of the aesthetic process” (2009, p.2). Among other examples, Tembeck discusses the work of artist Hannah Wilke, who suffered from lymphatic cancer. Wilke photographed herself in “the hospital in order to capture her now ‘grotesque’ body, and renew it once more into an artistic statement of self-affirmation” (Tembeck, 2009, p.88).

Similarly, Karolyn Gehrig, the creator of #HospitalGlam, “bridges advocacy and aesthetics through the fulcrum of her performative selfie practice” (Tembeck, 2016, p.5). Gehrig, who suffers from a debilitating chronic condition, uses her body and medical equipment to create editorial-like photographs. She makes her disabled body ‘fashionable.’ For example, a caption for one of the images “parrots the instructional rhetoric of makeover blogs, repurposing it for the benefit of patient empowerment [...] Gehrig writes, “#HospitalGlam tips: Color makes an impact and draws attention to your features. If you are advocating for yourself, drawing attention to your mouth is not a bad thing. Go bold. You’ll like it” (in Tembeck, 2016, p.6).

While there are performative aspects to Sophia and Daniel’s vlogging, unlike Gehrig, they are not mimicking or appropriating the poses and gestures of lifestyle vlogging. Rather, they are lifestyle vloggers. Their vlogs are also not performance art. Thus, a more appropriate framework to begin understanding cancer lifestyle vlogging and the online popularity of patients like Sophia and Daniel is the notion of entrepreneurial autopathography (Knudsen & Stage, 2015; Stage 2017; McCosker, 2013).

Stage identifies entrepreneurial tendencies in contemporary cancer bloggers who use their platform to generate economic and social value and mobilize online crowds. These patients, for example, produce content about their lives, help raise funds, coordinate events, and run online campaigns. Through their online storytelling, “cancer does not result in increasing passivity or social invisibility, but rather in various types of value creation using the narrative-affective force of the cancer experience to mobilize the public” (Stage, 2017, p.2). These bloggers may even “have some contact with professional media organizations, or have participated as speakers or writers for formal health industry-sponsored publications or events” (McCosker, 2013, p.139).

The blog 65redroses.com, run by Eva Markvoort, who suffered and died from cystic fibrosis, is an example of entrepreneurial autopathography. Markvoort amassed a large following, captured the attention of the news media, and participated in awareness campaigns to encourage organ donation. Knudsen and Stage (2013) describe Markvoort’s blog as having three phases. In the first phase, she writes about her life with cystic fibrosis and her worsening health condition. A second phase begins with her receiving a transplant, the temporary
improvement in the quality of her life, and the screening of a documentary based on her experiences. The third stage of the blog deals with her deterioration, the announcement of her terminal condition, and then, her death.

In addition to a chronological reading of the blog, Knudsen and Stage perform a second reading from the perspective of what they call ‘moments of intense affect.’ These moments result from Markvoort using “her body to create micro-shocks” (2015, p.34), including, for example, a video of one of her severe coughing attacks and her announcement that she is facing the end of her life. With regards to the latter, Knudsen and Stage highlight the outpour of love and emotion that the announcement generated in her followers.

Markvoort’s blog “challenge[s] existing cultural understandings of illness as something private, socially invisible, non-economic and perhaps even ‘non-vital’” (Stage, 2017, p.1). Not unlike Raun’s subcultural microcelebrities, Markvoort’s social media activity “is genuinely political, in the sense that an otherwise marginalised individual (the weak and sick person) and the crowd surrounding her succeed in pushing the boundary between private and political concern” (Knudsen and Stage, 2015, p.37).

My definition of stories of popular bodies builds on ideas about the entrepreneurial patient. Indeed, Sophia and Daniel defy the passivity associated with people who are gravely ill. They vlogged, travelled, documented their lives, engaged audiences, and created value – including for YouTube itself as a platform. However, in my analysis, I place the emphasis not just on this entrepreneurially, but also on the related condition of online popularity.

Online popularity is a form of platform-enabled visibility, which is supported and reflected by rankings and metrics. To be popular on YouTube is to be watched, commented, and followed, and thus to have an audience. Also, the more views a user has, the most likely their content will be promoted by the platform’s algorithms. Having an online audience has benefits such as knowing that one is being listened to, acknowledged, and liked —advantages that are also reflected by the platform’s upvote buttons and comments. This popularity serves as a commodity. People with large social media audiences are sought out, invited to events, and asked to collaborate.

To be popular online is also a measurable output of online labor and entrepreneurialism, two topics which I explored previously also the introduction of this book (see: Duffy, 2015; McCosker, 2013; Abidin, 2016). It depends on vloggers constantly updating their channels and engaging in audience management. By repurposing YouTube’s rankings one can identify which vloggers are doing well in the medium, as I have done by querying “cancer vlog” to identify Sophia and Daniel. It is also possible to know which videos in a channel generate
more engagement, if one chooses ‘popularity’ as the criteria to organize the channel. In sum, popularity is a way of looking at social media content that stays close to the medium culture and methods.

There are issues that need to be considered with respect to entrepreneurial and popular illness stories. For example, “far from simply or magically empowering an individual, the self-expression of illness requires significant labor” (McCosker, 2013, p.132). This labor is taken up by people whose energy is limited and can lead to exploitation. Also, as I later demonstrate, to be visible on YouTube is to make oneself vulnerable to critique, of which terminal patients are not an exception. In order to capture these complex dynamics of illness and online popularity, like Knudsen and Stage, I also perform a double reading, or more precisely, a ‘filtered reading’ of Sophia and Daniel’s vlogs, albeit with a different focus.

To Study Popular Bodies, Adjust the Filter Twice

The first reading I conduct here is chronological. It corresponds to how the vlogs is reorganized when using YouTube’s filter setting, ‘from older to newer’. Through this reading, I describe how each vlogger transforms their experiences with cancer into social media content, analyze the audio-visual content of the videos, identify key events and themes, and I monitor how these change as the illness progresses. I take into account the activity from the start of each vlog until the vlogger passing away. In this first reading, popularity is a part of the story. Thus, I look into how Sophia and Daniel used subscription buttons, comments, and Q&A videos to promote their channels and how they discussed their visibility and relationship with their viewers. Two visualizations support this analysis. In Figure 1 and Figure 2, respectively, one sees the videos produced by Sophia (83 videos) and Daniel (200 videos), each represented with a square and a number. The number indicates the position of the video in the vlog, from older to newer. To highlight key moments in the illness stories, I have added video titles.

In the second reading, I focus on the most popular videos as well as on the least active period in the vlogs. The most popular videos in both vlogs are the announcements that cancer has become incurable – posts which, in turn, generated a myriad of comments, including those critiquing illness vlogging as an activity. As their health declined, Sophia and Daniel produced less content (and engagement), which led to the judgment of their perceived authenticity. The vloggers felt compelled to manage a concerned audience and respond to comments. I utilize these hermeneutics of suspicion (Jurecic, 2012; Ricouer, 1970) as an occasion to reflect on the expectations placed on popular patients and how these, in turn, invite revisiting arguments about the restorative and empowering capacities of illness storytelling. To support the quantitative analysis of the vlogs, I employ the software tool ‘YouTube Data Tools,’ developed by Bernhard Rieder.
The tool retrieves structured data from YouTube channels. For each video included in a vlog, it downloads the title, description, time of publishing, and metadata, including the duration and number of likes, comments, and views it has received.

Studying social media accounts (including YouTube channels) through the lens of popularity is a simple yet efficient digital-methods technique. On the one hand, it follows the culture of social media, which values and encourages popularity. It also follows the methods of the medium, which calculate and valorize content that is viewed and commented. Rogers (2019) has explored Facebook pages using the same technique. He chooses “a Facebook page, or curate a set of pages, concerning an event or a social issue. From the beginning of the event or issue formation” and created a timeline of the most engaged-with content” (Rogers, 2019, p.200). The most engaging content helps explore moments that are controversial and that have animated public debate. Similarly, in the project ‘For the People of Iran #iranelection RT,’ which I reference in the introduction of this book, Rogers et. al. (2009) collected the most retweeted tweets that included the hashtag #iranelection and used them to create an account of the event.

Academic research about YouTube has mostly adapted ethnographic and narrative methods to the medium. For example, Chou et al. (2011) employ linguistically-based narrative analysis to study 35 personal cancer stories on YouTube. They found that diagnostic narratives are prevalent in the corpus. Similarly, Jacobson (2018) used Frank’s typology of illness narratives to profile the channels of four women with metastatic breast cancer. Also, Presswood et al. (2016), Hun et al. (2014), and Casañas et al. (2016a; 2016b) employed content analysis to study videos produced by patients with stage IV cancer and HIV. The focus on popularity sets this investigation apart from other work on end of life stories on social media.

Reading 1: Becoming Terminally Ill in Front of An Audience

Sophia’s and Daniel’s vlogs start as “restitution stories,” (Frank, 2013) driven by the goal of achieving health. Sophia suffers from osteosarcoma, has finished chemotherapy, and will travel to the United States for proton therapy. During this time, her vlogging follows the style characteristic of travel vloggers – that is, she brings her viewers ‘along for the ride’ by sharing packing tips and the details of her first-class flight. She also talks about her love for makeup and the importance that it has for her. For example, the title of the video, ‘Proton therapy + Shopping!!!’4, which is fifth on her channel (see Figure 1), reflects the dual nature of her channel. She documents trips to Starbucks and a visit to Disney

4 So Fia [Jan 22, 2016] PROTON THERAPY + SHOPPING!!! [YouTube video] https://www.youtube.com/watch?v=st5xKFBXTTc
World. Her attitude and tone are always ‘bubbly’ and positive, and illness appears only in the background.

After receiving numerous requests of curious viewers, Sophia begins to vlog more about her illness and, having completed treatment, uses her vlog to reflect on life as a former patient. She posts, for instance, the videos ‘My Cancer Story,’ in which she summarizes past events including her diagnosis, ‘DAY IN THE LIFE OF A CANCER PATIENT,’ ‘Normal people vs. people with cancer’ and the joyful, ‘I’M CANCER FREE!’ which is video number 30 in Figure 1. Afterwards, she also uploads poetry, speaks with a local magazine and wants to collaborate with makeup artists. Sophia is also explicit about her desire to reach more viewers and collaborate with other fashion and makeup content producers. For example, in her video descriptions, she includes the message: “If any businesses would like to work with or collaborate with me contact me” and she always reminds viewers to ‘hit the subscribe button.’

Months later, Sophia posts a troubling update: her cancer has returned. This update inaugurates a second phase in her story and channel. During this time, she vlogs from the hospital about side effects, pain, and the return of the feeding tube. She is heartbroken but aims to post “happy upbeat content” and engage with her viewers. Videos now include titles like: ‘Does chemotherapy hurt?’ and ‘Scans, Scans, Scans,’ respectively, number 46 and 51 on Figure 1.

Daniel was diagnosed with Pleomorphic Sarcomatoid Carcinoma. Frustrated by the lack of information about his condition, he argues that becoming a popular vlogger can help him gather new insights and educate people. Also, Daniel remarks that most cancer vloggers are women. He refers to Sophia’s vlog as an inspiration and suggests that his vlog might offer a different perspective. He reassures viewers: he will speak about cancer, but also intends to be funny and entertaining. His goals are posting daily, making good content, and creating a

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https://www.youtube.com/watch?v=1xl6c745fQI

6 So Fia [April 4 2016] ‘DAY IN THE LIFE OF A CANCER PATIENT // SO FIA’ [YouTube video]  
https://www.youtube.com/watch?v=4QK8cI-n3uw

7 So Fia [April 30 2016] ‘NORMAL PEOPLE VS PEOPLE WITH CANCER // SOPH FIA’ [YouTube video]  
https://www.youtube.com/watch?v=ufK6V7yJG5w Here and elsewhere you will format the footnotes I presume [see the blank lines]

8 So Fia [May 27 2016] ‘3 Words - I’M CANCER FREE! | SOPH FIA’ [YouTube video]  
https://www.youtube.com/watch?v=RxNkJe8d2eWI

9 So Fia [August 13 2016] I’M IN A MAGAZINE!!! + HUGE SHOPPING HAUL!!  
https://www.youtube.com/watch?v=q74dAn--9jQ&t=452s

10 So Fia [April 1 2017] ‘Does Chemotherapy HURT? | Snapchat Q & A’ [YouTube video]  
https://www.youtube.com/watch?v=HIraMnLq

11 So Fia [May 24 2017] SCANS, SCANS AND SCANS!! Day in the Life Vlog [YouTube video]  
https://www.youtube.com/watch?v=qOo0Rk1-mnM
community. During this time, video topics include the questions: ‘Doctors lie?’ and ‘what is cancer?’ (numbers 8 and 9 in Figure 2), as well as videos in which Daniel talks about the technical aspects of vlogging. He also documents his treatment and answers viewers’ questions. He is open about the pain and shows tumors and scars on the camera. Daniel is extroverted, uses humor, and describes himself as refusing to give up.

Neither Sophia nor Daniel started vlogging as a terminal patient. Rather they became one in front of their viewers. Sophia revealed that she was stopping treatment in the video, ‘My Cancer Is Worse Than Ever - Scan Results’ (number 52 in Figure 1). In this video, she looks directly at the camera and pronounces that she “can’t explain ... how painful this is” and that she plans to enjoy her life by traveling the world with her family. She asks for the viewer’s participation: “If you guys have any good ideas of what to do in those places, let me know in the comments”. She also thanks her viewers for their support: vlogging has enabled her to “get away from everything” and raise awareness. She concludes by remarking, “I have avocado socks, this will brighten your day,” and by asking her viewers to enjoy life, be positive, and believe in themselves.

Daniel published a similar video, titled ‘Cancer has won,’ which is number 177 in Figure 2. In the video he says: “They just told me it is inoperable now... I’m now documenting the end of my life.” Viewers see Daniel and his mother in their car. Looking directly at the camera, Daniel says: “nobody knows how long I have.” Daniel describes this video as the hardest one he has made. Daniel thanks his viewers for watching, commenting, and liking his videos. The video concludes with footage of Daniel and his mother driving to the hospital (at the time of the recording unaware of the results) and then shows their reactions immediately afterwards.

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14 So Fia [May 28 2017] 'My Cancer Is Worse Than Ever - Scan Results' [YouTube video] https://www.youtube.com/watch?v=69wLAbEY1YI&t=331s

15 PeeWeeToms [April 24 2018] 'CANCER HAS WON IT'S GAME OVER' [YouTube video] https://www.youtube.com/watch?v=9S902T1B6xE&t=287s
Figure 1: Sophia’s Vlog. On the graph are 83 videos from Sophia’s vlog, represented with a square and a number. The number refers to the order in which the video was uploaded to the vlog. The selection of videos illustrates aspects of the narrative and the type of content found on the vlog.
Figure 2: Daniel’s Vlog. On the graph are 200 videos from Daniel’s vlog, represented with a square and a number. The number refers to the order in which the video was uploaded to the vlog. The selection of videos illustrates aspects of the narrative and the type of content found on the vlog.
After announcing that their cancer was terminal and as their health declined, Sophia and Daniel’s content and narrative changed: they were now documenting the enjoyment of the time they had left. As announced, Sophia vlogged about her trip around the world, updating viewers from every location, and documenting concerts and meetings with other vloggers and celebrities. Indeed, at this point, Sophia is well known and her story is occasionally reported in the news. However, Sophia’s health quickly declines and she stops traveling. After not vlogging for months, she updates viewers: she has become bedridden.

After his terminal diagnosis, Daniel is determined to ‘fight’ for time and continue raising awareness. He documents his visits to the hospital and speaks about financial issues and struggles with body image. He does not feel like himself anymore; his energy and ambitions are gone, and he speaks only about how cancer has taken a toll on him. He promises to vlog about other aspects of his life too. He reassures his viewers: this is not about the end of life but about the continuation of life. He documents his visits to music festivals and the zoo, among other outings, even though he specifies that he carries on with these activities for short periods of time. Daniel also celebrates reaching 100,000 subscribers. Later, Daniel vlogs about palliative care, marrying his girlfriend, and about the messages of support that he receives from celebrities.

Reading 2: Low Productivity, Death, and a Concerned Audience

As said, after the chronological reading, I now perform a second reading, in which I approach the vlogs organized according to popularity and present the findings of that reading. I make the starting point of the analysis the videos that obtained the most views and comments in each of the vlogs. These videos and their comments and the video responses that followed, as I illustrate below, became spaces for discussing and contesting the particularities of vlogging about terminal illness and popularity.

‘My Cancer Is Worse Than Ever - Scan Results’ and ‘Cancer has won’, the videos in which Sophia and Daniel announced that their illnesses are incurable, are the most popular videos in both vlogs. Sophia’s video announcement received 2.2 million views and Daniel’s 2.4 million. After the vloggers’ announcements about their incurable diseases, viewers turned avidly to the comment section and would continue to do so for several months afterwards. In table 1, I have included a selection of comments left below these two videos announcements and which I use to examples in my analysis. In the table, I added a ‘light’ labelling to indicate some of the different types of comments found.
<table>
<thead>
<tr>
<th>Type of comment</th>
<th>Sophia Gall</th>
<th>Daniel Toms</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Support and sympathy</strong></td>
<td>‘Omg I wish I could hug you it will be ok’&lt;br&gt;‘Sophia, your avocado socks did brighten my day, but not as much as your beautiful smile’&lt;br&gt;‘Go to Thailand!’</td>
<td>‘Enjoy your life to the fullest man. Seize the day. Fuck cancer’&lt;br&gt;‘PeeWeeToms you deserve at least 1 million subscribers, man! Stay strong’</td>
</tr>
<tr>
<td><strong>Shared stories</strong></td>
<td>I went through chemo [...] I’m crying and even now I’m suffering. Let’s have a chit chat once we done with this cancer&lt;br&gt;Last year I lost my mother to cancer. I know how much It hurts</td>
<td>I am sorry that you have to go through this. My mother lost my older sister's dad to skin melanoma. It is hard</td>
</tr>
<tr>
<td><strong>Medical advice</strong></td>
<td>Sophia, there is a cure. Please look up the truth about Cancer both on YouTube and on the Internet&lt;br&gt;Can’t you amputate the leg to get rid of the cancer?&lt;br&gt;Amputation is not an option, her cancer has spread too far. Her cancer IS all in her body and she is at the end of her life. Nothing more can be done but please, tell her again how she should be thankful?</td>
<td>Put aside all the mainstream BS about cancer and go deep. Real deep. Go open minded into natural cures, but if you don't believe in what you're doing nothing will work. I cured myself of cancer by going alkaline&lt;br&gt;All these disrespectful people in the comments claiming they have a cure, like they're certified doctors with breakthrough remedies. Get over yourselves</td>
</tr>
<tr>
<td><strong>Religion</strong></td>
<td>I hurt for you. Do you know Jesus? Are you a Christian?</td>
<td>...after doctors found cancer cells ... all my mom did during that time was pray day and night and put her faith in god and then one day the doctor comes in ...the cells are gone</td>
</tr>
<tr>
<td><strong>Critique</strong></td>
<td>You still are lucky to be able to do a world tour. I couldn't afford that and the same goes for many other people in the world that are very sick. Wish you the best&lt;br&gt;there are rich and poor people ... you don't know her full story a 10-minute video doesn't explain her whole life and even if it is an expensive watch she deserves every last penny</td>
<td>You should really stop vlogging and be with your family and friends&lt;br&gt;Fake cry. U are one of those youtubers/streamers who fake injury to get donations. Pathetic&lt;br&gt;Chill man, takes a few minutes to make a video, not like it's filled with snazzy editing or anything, it's a simple video that he's almost treating like a diary</td>
</tr>
</tbody>
</table>
What if his fans are his family and friends as well? Let him do what he wants dude. If he likes vlogging let him do that and he can still be with his family.

<table>
<thead>
<tr>
<th>Troll</th>
<th>You are still here ????????......... children die. Stop crying and have some dignity. I want to see you are dying with cancer painfully</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Haha, Fucking die XD</td>
</tr>
</tbody>
</table>

| Table I: Comments on Sophia’s and Daniel’s videos. | A selection from the comments left under the videos ‘My Cancer Is Worse Than Ever - Scan Results’ by Sophia Gall and ‘Cancer has won’ by Daniel Toms, labelled according to type. Types include ‘support and sympathy,’ ‘shared stories,’ ‘medical advice’, ‘religion’, ‘critique,’ and ‘troll’. To protect the privacy of commenters, I have omitted their names. Comments where capture using the tool ‘YouTube Tools,’ designed by Bernhard Rieder. |

Through their comments, viewers offered support, shared their own stories of illness, and gave advice. At the same time, distrust in medicine was a common theme, with viewers commenting that a ‘cancer cure’ exists but is kept secret. Others questioned Sophia and Daniel’s medical choices. In the case of Sophia, commenters questioned her decision not to have her leg amputated. For example, one comment reads: “Can’t you amputate the leg to get rid of the cancer?” In addition, trolls left hateful messages wishing for the vloggers’ deaths, and some commenters reacted to the news by describing vlogging as a poor use of Sophia and Daniel’s limited time. One person says about Daniel: “You should really stop vlogging and be with your family and friends”.

Likewise, attacks come in the form of an accusation that both Sophia and Daniel are faking their illness to get attention and money. One person writes: “Fake cry. U are one of those youtubers/streamers who fake injury to get donations. Pathetic”. In Sophia’s case, her socioeconomic status becomes a point of discussion in the comment section. For example, an audience member says: “You still are lucky to be able to do a world tour. I couldn’t afford that and the same goes for many other people in the world that are very sick. Wish you the best.”

These types of remarks generated controversy in the comment section, with certain viewers defending the vlogger. Another commenter responds, for instance: “All these disrespectful people in the comments claiming they have a cure, like they’re certified doctors with breakthrough remedies. Get over yourselves.” Another user defends Sophia, “there are rich and poor people [...] you don’t know her full story a 10 minute video doesn't explain her whole life and even if it is an expensive watch she deserves every last penny.” This user is referring to the clothes and accessories that Sophia’s parents buy for her and that she shares in her videos.
After the announcements, Sophia and Daniel continued to build a relationship with their viewers by frequently producing content, maintaining story arcs, responding to questions, and encouraging discussions in the comment section. The content they produced was about illness as well as about their personal interests. In turn, viewers liked and commented on their videos. However, as their health declined, Sophia and Daniel became unable to vlog as frequently or in the same manner. Their channels grew quieter and metrics diminished. As a result, some viewers grew inquisitive. They expressed dissatisfaction because Sophia and Daniel allegedly did not post enough content and began speculating about their deaths or accused them of faking their illnesses in order to receive attention and money.

Both vloggers felt compelled to publicly respond to the accusations and reflect on the difficulties and constructed nature of vlogging. Indeed, for Sophia and Daniel vlogging also involved managing a concerned viewership at the end of their lives. More pointedly, after months of not posting and receiving negative messages, Sophia published a video response, titled ‘Health update + Q&A’.\(^\text{16}\) In the video, she explains that she has received many comments saying that she has purposely not been updating her viewers. Sophia expresses appreciation for her followers’ concern, but clarifies that she deserves her privacy “just as much as the next person”. Sharing her journey and life online does not give viewers “automatic allowance to know every single thing going on in my life. For those of you saying you subscribed to my channel for my Cancer story and not makeup and beauty, feel free to unsubscribe. I’m not forcing you to be here”.

After four months of silence, Sophia posts the video ‘Where I’ve been.’\(^\text{17}\) Sophia is at home and has done her makeup. This is a matter about which she also feels she needs to offer clarification. “I never look like this on a daily basis” — Sophia says — “I have done all of my makeup and I put on clothes and a beanie. This is not how I look every day. This is how I look for this video because I wanted to make myself feel pretty”. Indeed, Sophia is now virtually bed-bound and in terrible pain. She misses vlogging very much and is disturbed by the comments and messages she receives, especially those that assume she has died or that she does not care for her viewers. She has also been accused of vlogging just for fame. Sophia defends herself by saying: “now that I became famous, as people like to call me (I’m not famous) … They are saying that I’m using you guys”. She continues, now visibly affected: “Those comments are just so wrong. I mean, if you guys had seen what my life has really been for the past 4 months... seeing

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those comments... people have no idea what I’m actually going through”. Furthermore, when she posted to Instagram, Sophia received comments saying that it was not a “full update”. She pleads: “Please keep the comments positive if you can”.

She concludes the video by announcing that she has been nominated for a Shorty Award as a health influencer and invites viewers to vote, as winning such an award would mean a lot to Sophia and her family. She concludes the video by saying: “It would be an awesome thing for my family ... So they can remember my channel and all the hard work I put into it ... thank you all so much”. In a follow-up video, Sophia’s mother hands her the award. Shortly after, her family announces her death at the age of 17.

Daniel had to address similarly negative comments. Early on, he reveals that viewers often ask him if his illness is real. Because he “doesn’t look sick” and is not in chemotherapy, people doubt him. Likewise, his humor and positive attitude generate skepticism. In a video titled ‘cancer update 07-02-2018’18 Daniel clarifies that despite his humor in the videos, his reality is “not funny” and the pain “is unbearable, it’s crazy”. He says: “I let you see what I want you to see”. He apologizes if this is not the content his viewers want to see. In a follow-up video, he adds that he uses the comedy and the silliness more for his own benefit. On another occasion, he clarifies that he vlogs on the peak of his medicine and reflects on what he edits out. As his condition worsens, Daniel begins to vlog even less frequently. His updates are shorter, less edited, and he is out of breath. He asks viewers not to worry —he receives constant inquiries about his health— because if something happens, they will be notified. During the last days of his life, Daniel’s brother takes on the role of speaking to the camera. In September 2018, Daniel’s wife and family announce his death through his vlog. They thank viewers and remark on the positive impact that vlogging had on Daniel. They say they will continue to release content.

The Difficulties of Popular Bodies

Sophia and Daniel were illness storytellers and examples of what in media studies is known as microcelebrity (Senft, 2013; Marwick, 2015; Abidin, 2016). This last concept describes the production, curation, and publication of social media content about one’s personal life. The goal of this activity is to command attention and generate social and/or monetary value and it is, in essence, entrepreneurial.

For Sophia and Daniel, being a microcelebrity was meaningful. Not only did vlogging enable them to express themselves and create meaning at difficult

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moments in their lives. It also became a tool to connect with other people by having their stories listened to, followed, viewed, and commented on. Their vlogging also grew into personal and professional projects. These positive aspects of vlogging as a form of illness storytelling and of popularity may be linked with existing thinking about the capacity of storytelling to help patients deal with narrative wreckage and recover agency as explored by author such as Frank (2013) and Hawkins (1999). Indeed, Sophia’s and Daniel’s vlogs challenged notions of sick people as passive and invisible and pushed the boundaries of ‘what sick bodies are capable of doing’. Their stories started as restitution stories, that is, cure-oriented. Then, they resembled Frank’s idea of the ‘quest narrative’, which involves seeing beyond cure to find meaning, an aspect relevant to terminal illness. The vlogs documented Sophia’s and Daniel’s effort to ‘live life at its fullest’. Vlogging in itself emerged as a goal. Both patients committed to vlogging for as long as they could, at least based on what can be inferred from their discussions about it. For Daniel telling his story became a quest in its own right. Sophia, as I described earlier, similarly, saw her vlogs as her legacy.

Vlogging changed as Sophia and Daniel's health declined. After learning that their diseases had become incurable, Sophia and Daniel, as I mentioned, documented their commitment to enjoying their lives. The number of views and comments on these videos were seen by the vloggers as indications of the positive impact of their stories. Nevertheless, poor health did limit their capacity to keep producing content, which generated concern and suspicion amongst viewers. Both bloggers felt the need to address these comments and expressed a sense of discontent and pressure. In addition, as Sophia’s and Daniel’s health worsened, it became difficult for them to keep up with the interactions of their concerned viewership.

Other popular sick microcelebrities have also been subject to public scrutiny. Walker Rettberg (2014) wrote about the case of Lisa Boncheck Adams, who tweeted about her battle with cancer and was criticized by journalists from The New York Times and The Guardian. Adams’s social media illness storytelling was deemed as inappropriate and her visibility made the journalists uncomfortable. About Adams’ tweeting, one of them wrote: “Should there be boundaries in this kind of experience? Is there such a thing as TMI? Are her tweets a grim equivalent of deathbed selfies, one step further than funeral selfies? Why am I so obsessed?” (E. Keller, 2014)

Walker Rettberg describes these journalists as acting simply as “readers of a text, members of a large audience watching a performance” (2014, p.15). That Adams “live her cancer onstage” was seen by them as invitation to “think about it, debate it, learn from it” (B. Keller, 2014, in Walker Rettberg, 2014, p.15). However, these journalists appeared to have forgotten “that the texts we read in real time in social media represent actual, living people” (Walker Rettberg, 2014, p.15). It seems, put
differently, that to be popular online opens the door to having one’s one self-representations policed. However, unlike traditional celebrities, microcelebrities “do not have agents and PR consultants to protect them from the press and the public” (Walker Rettberg, 2014, p.16).

In the cases of Sophia and Daniel, the focus of criticism was not appropriateness but rather authenticity. As I mentioned before, microcelebrity is often dismissed as a form of aspirational and unauthentic production of the self. It is said to reflect how a person wishes to be seen and not who they are. After being accused of faking their illnesses or being disloyal to their audiences, Sophia and Daniel discussed publicly the edited character of their vlogging. Rather than an unmediated communication, their vlogs were, indeed, planned and edited. They also reflected choices about how they both wanted people to perceive them, as when Daniel remarked that being funny in the videos was empowering. For Sophia, using makeup (even if only to record the videos) made her feel good about herself and became an escape. To be able to alternate between frontstage and backstage personas, to use Raun’s terminology (2018), was actually appreciated by them, as seen in how Sophia sometimes vlogged as a beauty and travel influencer, and other times as patient. Sometimes she even spoke as both. Daniel raised awareness, documented his travels, and, as mentioned, produced merchandise branded with his mantra: Don’t Give In! Don’t Give Up!

As scholars in media and authenticity demonstrate, the question if a story is ‘truly’ ‘authentic’ or ‘fake’ is rarely productive: authenticity is mediated by default. In the words of one recent study, it is “the result of a careful aesthetic construction ... with the aim of achieving certain effects” (Funk et al., 2014, p. 10). This insight also matters to the editing in Sophia’s and Daniel’s vlogs. Rather than unauthentic, their editing can be conceptualized as a means to regain control and to express themselves in ways that are productive and true to their identities in and beyond patient-hood. In other words, vlogging and editing became means to recover a sense of narrative agency, often associated with illness storytelling. Based on their self-report, having such control over how people saw them and highlighting aspects central to their personalities was beneficial for them. However, based on the video responses that both Sophia and Daniel formulated, their difficulties were not evident, at least, to a number of viewers. These viewers, not unlike the case of Adams, also came to treat patients not only as content-producers but as content themselves – forgetting or not caring about how their viewer interactions impacted the vloggers. Addressing these types of interactions became a part of being a popular patient.

Microcelebrity and online popularity, as this analysis demonstrated, have a burdensome aspect and one needs to revisit claims about the empowering capacities of public storytelling vis a vis these conditions. Further research could investigate more in depth whether and how these new forms of public storytelling
can also become a tool to help (while not hindering) the dying and their caregivers.

What happened to Sophia and Daniel’s vlogs after their deaths? Asking such a question takes us away from the end of life and into “the management of the digital self after death” (Graham, Gibbs & Aceti, 2013, p.133). That is, the management of “how people are consumed, worked with, and viewed after death” (Graham, Gibbs & Aceti, 2013, p.134). Unlike the afterlife, the experience of (after-)death “is largely examined from the point of view of those healthy and alive” (Graham, Gibbs & Aceti, 2013, p.141). It involves, for example, a discussion about “a lingering sense of connection, presence, and responsibility for the living, a sense that social media ... can prolong, whether or not it is welcomed by the aggrieved” (Graham, Gibbs & Aceti, 2013, p.141).

Since her death, no new content has been uploaded to Sophia’s channel. Nevertheless, YouTube still returns Sophia’s vlog as a top result for the query ‘cancer vlog’ and it is recommended alongside other cancer-related videos. The number of subscribers to her channel continues to grow. As of January 2020, her channel has more than 163,000 subscribers, a couple of thousand more than when this research was first conducted. Her most watched video remains the announcement that her cancer is incurable. It now has 4.4 million views.¹⁹

On the other hand, Daniel arranged for his family to continue vlogging on his YouTube channel. Such new content includes clips from the memorial videos in which Daniel’s parents discuss their grief. In the comment sections of these new videos, the viewers who are still subscribed to the channel share their emotions. One of them writes, “damn it just feels strange now when I receive a notification from Danny... We miss you mate.” Another one says, “My heart dropped when I saw this notification.”

The vlogs continue to generate value and impact even in their (after-)death. There has been discussion about the response by social media platforms with respect to data protections and permissions (Leaver, 2013). In addition to this work, there are inquiries about those close to the deceased vloggers. How to “understand the expressed hurt some bereaved feel when not receiving enough likes or visitors at the site of their commemoration? [...] What type of security or consolation lies in a number?” (Lagerkvist, 2019, p.15-18) As vlogging about cancer gains popularity as a form of coping and some patients become popular, questions such as these become even more relevant. In the next chapter, I expand the question of health and bereavement – however, not with a focus on individual accounts and microcelebrity but on networked publics on Instagram.

¹⁹ February 12 2020
Chapter 3 Tagged Bodies and Wounded Healers
If you are on Instagram, you might learn about one of your friend’s pregnancies through an announcement post. These posts typically include the photograph of a sonogram or a positive pregnancy test, a caption, and hashtags such as #pregnant and #babyclub. To create these hashtags on Instagram, one simply places the number sign (#) before a word.

Later on, your friend will upload time-lapse videos to share the growth of her stomach and take the “perfect pregnancy selfie” (Austin, 2014, para. 7). She will also use online services that make tracking the fetus “a playful, creative and fulfilling experience” (Lupton & Thomas, 2015, para. 2). For instance, Baby Sizer is a service that helps expectant parents visualize the size of the fetus using familiar objects. According to the initiators, a fetus is like “a rainbow sprinkle in week 6 of pregnancy, a golden snitch in week 10, or a stick of travel-size deodorant in week 15” (Baby Sizer, 2020, para. 1). If you query Instagram for the hashtag #babysizer, you will find people posting screenshots from the service to update their followers.

Days (or hours) after the birth, you will see photos of your friend’s newborn on your content feed and, from then on, snippets of her life as a parent. When the publication of the child’s life is too detailed, people might call it ‘sharenting’ (Blum-Ross & Livingstone, 2017). There is also the chance that your friend will gain a sizable online following and become a ‘mommy influencer.’ She could offer tips about caretaking and promote brands on her Instagram account (Abidin, 2015).

Practices like these have led scholars to describe Instagram and other social media as spaces for the performance and “self-construction of pregnancy” (Tiidenberg & Baym, 2017, p.1), “mediation of childbirth,” and the articulation of “networked maternal subjectivities” (Das, 2017, p.1). There is also academic interest in discourses developing on social media around pregnancy and motherhood. For instance, Tiidenberg and Baym describe pregnancy today as “highly visible, intensely surveilled, marketed as a consumer identity, and feverishly stalked in its celebrity manifestations” (2017, p.1). With this in mind, they ask whether, on Instagram, women “rely on and reproduce pre-existing discourses aimed at morally regulating pregnancy, or reject them and construct their own alternatives” (2017, p.2).

Tiidenberg and Baym found, for example, that the selfies that Russian pregnant women post often emphasize their ability to remain attractive. This is known as the ‘yummy mummy’ phenomenon. Other studies, in comparison, identify counter-discursive practices, such as breastfeeding online activism (Locatelli, 2017; Mecinska, 2018; Meer, 2019).
In this second chapter, I, too, discuss pregnancy, birth, and motherhood on Instagram, though from a different perspective. I am interested in how women use Instagram to speak about stillbirth, which is the birth of an infant that has died in the womb after twenty-four weeks of gestation.

Stillbirths are linked to congenital problems, with or without a chromosomal abnormality, issues with the placenta, and conditions such as preeclampsia ("Causes" 2019). They are relatively frequent in western industrialized societies. For example, in the United States, it is reported that 1% of all pregnancies result in stillbirth ("What is Stillbirth? | CDC" 2019) and in England, 1 in every 200 births ("Stillbirth" 2019). At the same time, stillbirth remains a disenfranchised and invisible birth narrative. That is to say, the event is usually “not openly acknowledged, publicly mourned or socially supported” (Doka, 1989, p.4; Kelley & Trinidad, 2012; St John, Cooke, & Goopy, 2006; Murphy, 2012; Brierley-Jones et al., 2015).

With this social reaction in mind, it is intriguing to see how Instagram has become a tool to ‘break the silence’ about stillbirth and other forms of perinatal death. For example, maternity blogs advise readers to go to Instagram and use hashtags such as #stillbirth and #stillbornstillloved (‘stillborn still loved’). The goal is to “find other momma’s who may have had the same type of loss” (Mannegren, 2018, para. 8). Other similar hashtags include #bereavedmothersday (‘Bereaved Mother’s Day’), #angelmommies (‘angel mommies’), and #1in4. The last hashtag refers to the claim that “as many as 1 in 4 known pregnancies end in miscarriage, also known medically as spontaneous abortion” (Starr, 2018, para. 4).

Stillbirth and its alienation have inspired distinctive posting and hashtag practices, of which I will be discussing three. I identified these three practices by analyzing a collection of Instagram posts on the subject of stillbirth and explore them further using co-hashtag network analysis. Co-hashtag network analysis is a technique that combines the study of the cooccurrence of hashtags with the close reading of content.

In the first practice, bereaved patents participate in hashtag campaigns that help create rituals and render otherwise invisible grief ambient and networked. An example is Wave of Light, a candle-lighting ceremony for deprived parents that takes place during International Pregnancy and Infant Loss Remembrance Day. The organizers of the event instruct participants to “take a photo of [their] candle and post it to Facebook, Twitter or Instagram using #WaveOfLight” (“Get involved with” 2018, para. 5).

In a second hashtag practice, hashtags not only aid information discovery but also meaning-making, and help frame pregnancy loss and birth as journeys. For example, a person will experience pregnancy differently when their previous
pregnancy resulted in stillbirth or miscarriage. Through hashtags such as #pregnancylossjourney (‘pregnancy loss journey’) women share their personal histories encompassing multiple events —and the need to recognize and discuss them together— including miscarriage, infertility, stillbirth, and live birth.

Lastly, hashtags related to stillbirth and pregnancy loss are used commercially by an industry of makers to reach potential consumers and promote a material culture around loss. In many instances, the Instagram accounts using these promotional hashtags are run by small entrepreneurs who have themselves experienced some form of loss.

By ‘telling the story’ and tagging it in the ways I describe, women who have had a stillbirth, I argue, are practicing a form of ‘wounded healing’ (Frank, 2013). The latter is a concept from the field of illness narrative that describes how people who suffer regain agency as healers, create publics, and function as educators, in this case, through online storytelling and tagging. I call these stories, stories of tagged bodies.

Numerous studies have explored the formation of communities and tagging practices around health issues on Instagram and similar platforms. These studies address, for example, Instagram communication about fibromyalgia (Berard & Smith, 2018; Isika, Mendoza & Bosua, 2020), endometriosis (Melander, 2019), mental health (Feuston & Piper, 2018), Celiac disease (Meleo-Erwin et al., 2019), HIV (Nobles et al., 2020) and, on Tumblr, chronic pain (Gonzalez-Polledo, 2016).

My research contributes to this cluster of work. It has been argued that the narratives of pregnant women “can be seen within the wider context of illness narratives because they do share many of the same features, such as interactions with medical professionals and institutions, and sometimes unpleasant or traumatic interventions and practices” (Davis, 2014, p.260). Examples of these experiences are postpartum depression (Montgomery et al., 2012), illness resulting in infertility (Neville-Jan, 2004) fetal issues (Sandelowski & Corson Jones, 1996), and, indeed, stillbirth and other forms of perinatal death (Miller, 2005; Bailey, 2001). Like people who are seriously ill, women who have had a stillbirth face the challenge of making sense of their experiences as more than medical events.

Instagram also inspires investigations on what Tamar Leaver and Tim Highfield (2020) call lifespans. This involves the study of Instagram in terms of “uses and use practices that span an entire lifetime, from the cradle to grave,” with case studies on the very young and recently deceased (Leaver & Highfield, 2020, p.175). On the earlier spectrum are the studies on birth and maternal subjectivities that I referenced earlier. Leaver and Highfield have researched people’s motivations for posting sonograms on Instagram and the documentation of childhood. On the end side of the spectrum, are practices related to the end of life such as taking
funeral selfies, a new Instagram ritual for celebrating life and death, also researched by Leaver and Highfield. Stillbirth collapses such distinctions between the very young and the diseased, thus opening a different interrogation about mediated lifespans and the use of social media.

Stillbirth and, more generally, pregnancy loss also complicate discussions about personhood and grief. In my analysis, I follow the approach put forward by Lind (2017) and Earle et al. (2012), which rejects an *a priori* hierarchy of grief based on fetal growth and, instead, places the experience of the “gestating subject” at the center (Lind, 2017, Introduction). That means that choices about grief and its impact should be made by the person who was pregnant and not by the researcher. Accordingly, I follow closely the language of the online communities whose activities I study and describe how *they* identify their unborn and grief, rather than intending to settle any form of debate about grief hierarchies, or in other words, about whose grief matters the most.

On the following pages, I expand on concepts of disenfranchisement of stillbirth, social-media tagging in relation to illness storytelling, and wounded healing. Specifically, I review and build on Gonzalez-Polledo’s (2016) work on the tagging practices of Tumblr users who suffer from chronic pain and on Zappavigna’s (2018) theory of hashtags as ‘searchable talk’. Next, I explain the technique of co-hashtag network analysis and how I have employed it and present an account of each of the hashtags practices I mentioned above; namely, hashtags for making grief visible and networked; hashtags that articulate journeys; and hashtags for promoting commerce around pregnancy loss. In the conclusion, I return to Frank’s (2013) theory of wounded healing.

**Tagging pain and loss**

People with chronic pain are subject to testimonial and hermeneutical injustice (Carel & Kidd, 2014). When they share their experiences in health contexts or with peers, often, these are “met by prejudice [and] their frames to communicate about illness are deemed irrelevant, time-consuming, emotional, insufficiently articulate, or unhelpful” (Gonzalez-Polledo, 2016, p.2). Moreover, chronic pain is difficult to describe and it challenges dominant health narratives about a cure and progress. As a result, the experience becomes disenfranchised.

Gonzalez-Polledo studied chronic pain communication on Tumblr and Flickr, two visual social-media platforms. In both, she found people living with pain who “actively resist epistemic injustice and create inhabitable pain worlds” (Gonzalez-Polledo, 2016, p.2). People do so, for instance, by sharing visual metaphors and pain memes. A case in point is the photograph of a man, edited to appear as if his head was engulfed by flames. Many of these memes, Gonzalez-Polledo remarks, “elaborate recurrent themes of being ‘stuck’ in pain, ‘lost’ or
incommunicated, and on the idea that being overcome by pain is like being ‘out of control’” (2016, p.5).

The infrastructures of Tumblr and Flickr are crucial to create this shared pain vocabulary. Their public nature enables people to speak “about chronic illness in their own language” (Gonzalez-Polledo, 2016, p.7). In addition, “tagging images makes them searchable by keyword, meaning they may be encountered out of context, near other images with the same tag” (Gonzalez-Polledo & Tarr, 2014, p.1458). Thus, the result of this meme-making and tagging is a user-generated system of classification for content about pain. To study this folksonomy, Gonzalez-Polledo collected memes tagged with ‘chronic pain,’ ‘pain,’ ‘hurt,’ ‘migraine,’ and ‘fibromyalgia,’ and conducted a visual thematic analysis.

Moreover, Tumblr activity around chronic pain helps sustain the ‘spoonie networked public’. A public is a collection of people who have “a common understanding of the world, a shared identity, a claim to inclusiveness, [and] a consensus regarding the collective interest” (Livingstone, 2005, p.9). In the case of ‘spoonies,’ a shared identity emerges around the term ‘spoon,’ which reworks the pain theory formulated by Miserandino (Cristol, n.d.). The theory states that “living with a chronic illness means one has a limited amount of spoons (units of energy) which have to be carefully administered” (Gonzalez-Polledo, 2016, p.5).

The work involved in acting as a ‘spoonie public’ – that is, in creating a shared identity – is “restructured by networked technologies” (boyd, 2010, p.39). In the case of spoonies, a shared identity is the result of posting, making memes, and tagging content about chronic pain. This public is not either on- or offline: it exists simultaneously in “the space constructed through networked technologies ... [and]... the imagined collective that emerges as a result of the intersection of people, technology, and practice” (boyd, 2010, p.39).

In Gonzalez-Polledo’s study, networked content became “a key unit of analysis” (2016, p.3). Here, it seems important to understand the reblogging practices of spoonies. To unpack these, Gonzalez-Polledo used Tumblr’s API to collect posts tagged with ‘chronic pain’ and “metadata about the post (such as the user name, the post date, the post URL) [...] and a ‘reblog key’” (2016, p.5). Then, she produced a series of ‘re-blogging trees’ and analyzed them. In these trees, “each ‘nerve branch’ depicts how content (i.e. image, animation, video, etc.) is re-blogged throughout a community of people with chronic pain on Tumblr. When clicking on different ramifications of a branch a pop-up window will show a different context (a blog) in which the same piece of content has been re-blogged” (n.d. para. 1).

The Instagram activity around stillbirth that I study is also an example of social-media users creating networked publics and resisting testimonial injustice. About
stillbirth, feminist studies remark that “women whose infant children have died struggle to reconcile a pregnancy and state of motherhood that does not follow a standard narrative for pregnancy: conception, growth, and birth” (Bhave, 2017, chapter 5). Since the only expectation is birth and ‘reproductive success,’ women experience pregnancy loss and stillbirth as personal failures and deviations (St John, Cooke & Goopy, 2006).

Feminist scholar Karen O’Donnell (2017) elaborates on this idea of failure while writing about her full-term pregnancy loss. After the event, she remembers telling herself: “You have failed many times at this whole motherhood thing: you can neither produce a living child nor deliver her properly [...] You yourself almost certainly killed your baby by not paying enough attention” (O’Donnell, 2017, chapter 11).

Traditionally, pregnancy loss is not only framed as a failure, but also as inconsequential. Many people “view stillbirth children as never living” (Bhave, 2017, chapter 5). Accordingly, the dominant script is that after a stillbirth those involved should “return to normal life more quickly than following other kinds of bereavement” (Brierley-Jones et al., 2015, p.152) and avoid too much discussion about the death (Davidsson Bremborg, 2012). In other words: repairing the narrative wreckage caused by stillbirth needs to be quick and private.

The perceived right of a person to call themselves a ‘mother’ after a stillbirth is also contested and lacks nomenclature (Browne, 2016; Brierley-Jones, Crawley & Lomax, 2014). Elaborating on this “ambiguous space of motherhood,” feminist scholar Maya Bhave asks: “what happens if you lose a child in utero or near delivery? [...] Are you called a non-mother or post mother after such an event? [...] and, how to "continue mothering a child that is not present"? (Bhave, 2017, chapter 5). The dilemma “is troubling and is not voiced within society” (Bhave, 2017, chapter 5). Bhave argues that this leaves women limited options for discussing “what mothering with loss looks like” (2017, chapter 5).

Telling personal stories helps break the silence about stillbirth and expands the perceptions and ‘scripts’ available for making sense of it. Stillbirth storytellers include parents and the organizations that support them. Examples in the United States are the Angel Names Association (ANA) and the charity-funded “Stillbirth Stories,” a digital archive that offers “interviews with parents and clinicians talking about their experiences of stillbirth” (Stillbirth Stories, 2017, para. 1). News media also offer sharing platforms: in 2015, the New York Times asked readers to share their experiences and published the compilation, Stillbirth: Your Stories.

When the same stories are shared online, the storytelling can have various functions. When it comes to personal blogging, researchers have found that
motivations include therapeutic benefits and making available the “less frequently
discussed possibilities in the journey to parenthood” (Sohr-Preston & et al., 2016,
p.17). Instagram, as I have mentioned, is another online medium for speaking
about stillbirth and contesting the disenfranchisement of its grief. An
investigation is warranted to understand better how women are using the platform
to re-articulate their experiences beyond medical events and deviations from
normative narratives of reproductive success. It helps us to answer the question:
how is storytelling on Instagram becoming a vehicle to consider motherhood,
birth, and death in a “redefined scope?” (Bhave, 2017, chapter 5)

In what follows, I start my analysis by introducing the research methodology.
Like Gonzalez-Polledo, I explore tagging and posting practices as meaningful for
storytelling about health and as tools for resisting disenfranchisement. However,
while Gonzalez-Polledo mapped re-blogging trees, I employ hashtags and co-
hashtag networked analysis. A co-hashtag network analysis has similarities with
co-word analysis, a content-based bibliometrics technique that employs “structural
features of the network” to gain insights from a textual corpus (Chiu & Lu, 2015,
p.1). Researchers use, for example, the technique to examine “the co-occurrences
of the term/keyword pairs from titles, abstracts, keywords field, and/or the full
text in order to reveal themes, structures, and development of a field” (Chiu &
Lu, 2015, p.2). While co-hashtag network analysis similarly uses structural
features to gain insights, the network is not made of words but of hashtags. To
understand the network, one also needs to understand hashtags.

Hashtag theory: what do hashtags do?

In her book *Searchable Talk* (2018), linguist Michele Zappavigna, who I mentioned
earlier in my introduction, explores how hashtags have captured both the public
imagination and academic interest. The “practice of tagging, once an act of
classification,” she argues, also “has emerged as a means of forging and contesting
social bonds” (Zappavigna, 2018 p.1). By this, Zappavigna means that hashtags are
tags and forms of user “generated metadata,” which facilitate information
discovery, management, classification, retrieval, navigation, and the description
of content. Moreover, tagging supports a “decentralized practice by which
individuals and groups create, manage, and share terms” (Zappavigna, 2018, p.4).
In Gonzalez-Polledo’s study, as I already explained, this type of folksonomy was
a meaningful feature in the communication of people with chronic pain on Tumblr.

As Zappavigna demonstrates, in addition to classification hashtags have meaning-
making and social-bonding capacities. That is to say, people use them to create
semiotic meaning by adding context and extra-experiential information and
referencing perspectives. With this capacity in mind, people think carefully about
which hashtag is “most appropriate for the task of promoting visibility” (Page,
2012, p.183). That is, “using a particular hashtag presupposes that there exist other texts that may contain the same tag, as well as putative listeners who might ‘tune in’ via the social stream” (Zappavigna, 2015, p.288).

By bringing together information discovery and meaning-making affordances hashtags make “searchable talk” (Zappavigna, 2015, p.274) and invite “potential interaction with other members of the site” (Page, 2012, p.184). These interactions are not conversational. Instead, they are forms of “ambient affiliation” and “communing affiliation” (Zappavigna 2011, p.790; Zappavigna & Martin, 2017, p.4). With these terms, Zappavigna describes how knowledge about others and the co-presence and identification with these ‘listeners’ become tangible when one clicks on a hashtag and is redirected to thematic streams and networks of related content.

Hashtags help users, in this sense, in inserting themselves into thematic spaces and aligning “around values in social media” (Zappavigna & Martin, 2017, p.4). To track these acts, one can perform positioning analysis by “locating and placing the actors’ purposive keyword choice (or issue language) vis-à-vis that of others” (Rogers, 2018 p.12). An example: in the context of the same-marriage debate in the United States, Rogers was interested in the hashtags #lovewins (‘love wins’), favored by liberals, and #jesuswins (‘Jesus wins’), favored by conservatives. He saw an opportunity to determine “who is joining a program and who is joining an antiprogram” (Rogers, 2018, p.461-62) and use this information to describe the formation of “ad-hoc publics,” “calculated publics,” “hashtags publics,” and “networked publics” (Bruns & Burgess, 2015; Bruns, Moon, Paul & Münch, 2016; Papacharissi & Oliveira, 2012). These terms refer to the assemblages of users and content and communities of interest that are sustain by hashtag-usage.

The different ways in which Zappavigna approaches hashtags — information discovery, semiotic, and grouping devices—guide the co-hashtag network analysis, which is the technique I employ in my own work.

Co-hashtag network analysis

As mentioned, I began my analysis by creating a collection of Instagram posts. To accomplish this, I employed the software tool ‘Visual Tagnet Explorer’ to query Instagram and collect posts that contain either the keyword or hashtag #stillbirth. I performed the query on 3 July 2017 and collected 7,433 posts that had been published between February and July 2017. The quantity of posts corresponds to a randomized selection determined by Instagram’s API. The posts collected were authored by a total of 1537 unique public Instagram accounts. Most of them were run by women based in the United States, the United Kingdom, and Australia. In the ‘bios’ or posts, they disclose their connection to stillbirth. The authors have either experienced one or they are engaged in commerce or charity.
For each of the posts, the ‘Visual Tagnet Explorer’ captured the number of comments and likes, the text found in the caption, geolocation, timestamp, and hashtags. The tool makes this data accessible as a spreadsheet. The ‘Visual Tagnet Explorer’ also outputs a co-hashtag network based on the data. In this network, nodes are hashtags and edges appear between them to indicate that they cooccur, that is, that they are used together in a post. I used this co-hashtag network (and Gephi, a software for network analysis) as tools for making sense of the data and guiding my exploration of tagging practices in the stillbirth community.

In more detail, with Gephi, I ‘cleaned’ the network by eliminated #stillbirth, which is the query node to which every other hashtag in the network is connected. Then, I filtered the network to remove hashtags with a low frequency. In the case of the stillbirth co-hashtag network, I eliminated hashtags below a frequency of 10. Next, to explore the topography of the network, I used Force Atlas 2. This algorithm pulls to the centre of the graph the nodes with a higher degree count, which is the number of edges that are adjacent to the node. Then, with Gephi’s modularity function, I identified clusters of tightly connected nodes/hashtags. When applied to the stillbirth network, this function resulted in 14 clusters, numbered 0 to 13. Gephi provides an additional table in which one can clearly see which nodes (hashtags) belong to which clusters.

Below, in Figure 3, I share the co-hashtag network, with the main clusters differentiated by color. The resulting network is closely knitted, that is, there is no extreme polarization between the clusters, thus they remain close to each other in the graph. This distribution indicates that the occurrence of hashtags is frequent. The topography of the network — the clusters— support a form of ‘distant reading’ of the dataset and the discovery of a combination of hashtags and patterns significant for the analysis.

To contextualize the clusters and the patterns they evoke, I zoom into posts associated with the hashtags in each of the clusters, perform a close-reading of them, and, then, label the clusters. It is worth emphasizing that, in other forms of analysis, researchers study the entities first and then group them based on similarities. In this case, Gephi’s modularity function did the clustering of the hashtags. I looked into the clusters to answer the question: what do the hashtags in these clusters have in common? And what activities do they sustain? Ultimately, in co-hashtag network analysis, the topography of the network is used as a map for the qualitative exploration of data, taking into account content and hashtags, while the mathematical functions of the graph are “bracketed” (Venturini et al., 2017, p.156). Here, the concern is not so much with the exact value of gravity or connectivity but with “the stories that [networks graphs] evoke” through close reading (Venturini, Bounegru, Jacomy & Gray, 2017, p.157).
Figure 3: #stillbirth co-hashtags network. 7,433 Instagram posts are visualized as a co-hashtag network. In this network, nodes correspond to individual hashtags. Edges appear when hashtags co-occur in a post. To enhance visibility, the hashtags #stillbirth has been removed from the network, as all other hashtags are connected to it. This and the other graphs in this chapter were compiled with help of the ‘Visual Tagnet Explorer’ and Gephi software tools.

I characterized and labelled the 14 clusters taking into account the network topography and the associated hashtags and posts. To ensure the legibility of these findings, which I present below, I label and describe the clusters and hashtags practices without using the standard format for writing hashtags – the number symbol (#) before a word. Instead, I present hashtags in plain text in the table and between single quotations in the rest of the chapter. In table 2 I outlined the labels for each of the clusters and included a sample of the hashtags (nodes) that belong to them.
<table>
<thead>
<tr>
<th>Cluster</th>
<th>Examples of hashtags found in the cluster</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 Makers &amp; Support</td>
<td>Crochet, help others, cherished gowns UK, charity, bereaved parents, stillborn awareness, stillbirth support, still loved, baby loss support, neonatal death, angel baby, wrapped in love, volunteers, wedding dress, wrapped in love blankets, wedding dress upcycle, knitting love, cherished gowns</td>
</tr>
<tr>
<td>1 Hope &amp; Pregnancy Loss</td>
<td>Faith, angel mommy, infertility, hope, ivf, strong women, ttc journey, ttc sisters, miracle baby, ivf journey, forever loved Happy Mother's Day, rainbow babies, ivf sisters, surviving stillbirth, infertility sisters, April's fools, gestational surrogate</td>
</tr>
<tr>
<td>2 Rituals</td>
<td>Grief journey, what heals you, support, Mother's Day, mama grief, 1 in 4, bereaved mother, life after loss, stillbirth awareness, still born still loved, may we all heal, Bereaved Mother's Day, International Bereaved Mother’s Day, capture your grief, wave of light 2017</td>
</tr>
<tr>
<td>3 Motherhood in Loss</td>
<td>Stillborn but still loved, pregnancy loss awareness, angel babies, motherhood, still a mother, parents of angels, miscarriage matters, stillbirth matters, grieving mom, still mother, no more taboo, pregnancy loss group, I miss my son, always remembered, I am a mother, I am a father, Mother's Day 2017</td>
</tr>
<tr>
<td>4 Art &amp; Charity</td>
<td>Postcards to heaven, angel gowns, artist, handmade, still birthday, pencil drawing, keepsakes, non-profit, keepsake, angel gown project, hand crafted</td>
</tr>
<tr>
<td>5 Grieving Out Loud</td>
<td>Grieving parents, grieving father, stillbirth break the silence, say their names, still a mama, grief and loss, grieving, bereavement, grieving mother, child loss, mourning, wish you were here, in loving memory</td>
</tr>
<tr>
<td>6 Pregnancy After Loss</td>
<td>Third trimester, parenting after loss, pregnancy, pregnancy after loss, pregnancy, rainbow baby, born too soon, NICU, living with hope, birth trauma, breastfeeding, life after baby loss</td>
</tr>
<tr>
<td>7 Unfiltered</td>
<td>Mom life, raising, toddler, candid childhood</td>
</tr>
<tr>
<td>8 Identity</td>
<td>I am the 1 in 4, grieve out loud, loss and love, miscarriage survivors, empty arms, rainbow mama, baby loss mamas, miscarriage survivor, grief support, I had a miscarriage, grieving mama, bereaved moms</td>
</tr>
<tr>
<td>9 Connecting</td>
<td>Pass it on, soul tears, we understand, be you, life quotes, compassion, kindness, saying goodbye, you are not alone</td>
</tr>
<tr>
<td>10 Religion &amp; Inspiration</td>
<td>Wave of light, writers of Insta, authors life, I am writing, empowering women, Jesus cares, expecting sunshine documentary, Jesus heal, Jesus is lord</td>
</tr>
</tbody>
</table>
Table 2: Clusters with examples of hashtags. The 14 clusters found in the co-hashtag network are labelled included in the table, along with examples of hashtags associated with them.

In the clusters Rituals, Grieving Out Loud, and Memorialization one finds posts about recovery, grief, therapy, healing rituals, and bereavement. These clusters include hashtags celebrating events such as ‘Bereaved Mothers’ Day 2017’ and campaigns like ‘may we all heal,’ a photography challenge. Other hashtags and images evoke the memorial iconography specific to infant loss; examples are ‘tiny feet’ and ‘angel babies’. Similarly, in Motherhood in Loss, the content and hashtags emphasize the right to grief and claim the title of mother despite the loss of the stillborn child. In this cluster, one finds hashtags such as ‘still a mom,’ ‘I am a mother,’ ‘I am a father,’ and ‘Mother’s Day 2017.’ Closely related, in the clusters Identity and Awareness, are hashtags and content about self-identification and disclosure. These include ‘I had a miscarriage,’ ‘I am the 1 in 4,’ ‘baby loss mamas,’ and ‘breaking the silence.’ I return to some of these grief and awareness oriented clusters and hashtags when discussing the first hashtag practice: the creation of rituals that make grief ambient.

In the cluster Pregnancy Loss and Hope one finds posts discussing and sharing experiences about stillbirth, infertility, and other instances of perinatal death such as miscarriage, as well as the hope for a live birth. These posts make reference to journeys and communities: they include such hashtags as ‘pregnancy loss journey,’ ‘ttc journey,’ ‘recovery,’ ‘ivf journey,’ ‘ttc sisters,’ ‘infertility sisters,’ ‘strong women,’ and ‘ivf community’. In the cluster Pregnancy After Loss one finds, instead, discussion about becoming pregnant after a stillbirth. Hashtags include ‘there is hope’ and ‘rainbow baby’. Rainbow baby is the term used to describe a live birth after a previous loss. That is to say, the rainbow after the storm. I return to these journey-oriented hashtags and the storytelling they support when discussing the second hashtag practice.

The clusters Makers and Support, Religion and Inspiration, and Art and Charity include posts promoting the work of crafters, businesses, and charity enterprises dedicated to supporting grieving parents. These posts feature, in combination with the hashtag ‘stillbirth’, hashtags such as ‘donate a wedding dress,’ which refers to a
campaign looking to up-cycle wedding dresses into outfits for (diseased) newborns. Similarly, the hashtags ‘wrapped in love’, ‘handcraft,’ and ‘volunteers’ are included in posts published by Cherished Gowns UK, which “provides the families of babies that are stillborn, miscarried or pass away shortly after birth with items of clothing that they are able to be dressed in for their funeral” (‘Cherished Gowns’, 2020, para. 2). Here one also finds clothing brands that sell t-shirt with slogans such as ‘rainbow momma’, and post promoting Expecting Sunshine, a documentary that “chronicles the anticipation and anxiety of expecting a baby while still grieving for the child that came before” (Chute, 2017, para. 3). I use examples from these clusters to discuss the third hashtag practice: the creation of material and commercial cultures around pregnancy loss.

The last three clusters in the network are somewhat generic and dispersed and, thus, are labelled lightly, and left out of the analysis. The cluster Unfiltered reunites hashtags such as ‘keep it real,’ which are used for speaking about everyday life as a mother, but also about the realities of grief. In Spanish, one finds hashtags similar to the ones in the other clusters, but in the Spanish language. The frequent combination Spanish and English is most likely a product of the presence of users from the United States, where the two languages are spoken. Connecting includes miscellaneous hashtags and content such as ‘life quotes’.

In the next section, I describe and analyze in more detail the three hashtags practices that have my interest, using selected examples from the 14 clusters. In presenting my findings, I have isolated clusters from the co-hashtag graph in order to make legible the stories that they elicit. When refereeing specific posts, I chose not to include the names of individual Instagram users, with the exception of businesses. The few images I use to illustrate the main points of the analysis, have been edited to show only the silhouettes. On the practice of image editing that I follow in doing so, see Tiidenberg and Baym (2017) and Cesare and Branstad (2017).

Using hashtag campaigns to make #grief ambient

Parents create memorial websites for their stillborn babies. These websites feature portraits taken at the hospital, accounts of the birth, sonograms, and artworks. According to visual researcher Margaret Godel, materials such as these helps tell an imagined story “of the baby’s life, not from birth onwards, but from conception to birth which is also a death” (2008, p.263). Creating the website also helps parents integrate the birth into their social world and “work through grief and mourn” (Godel, 2008, p.260). This therapeutic function of memorial sites is important, considering that “there are few rites for those who have been born but never lived” outside of the womb (Godel, 2008, p.258).
Memorial websites support forms of reciprocal acknowledgment. According to Godel, memorial websites tend to link to each other and parents leave entries on each other’s guestbooks and ‘grant awards.’ These awards “are a form of recognition for the stillborn baby [and] take the form of virtual plaques” (Godel, 2008, p.264). Their presence increases “traffic to particular sites and perpetuates the spread of virtual networks of interest” (Godel, 2008, p.264).

Activity around stillbirth on Instagram resembles, to some extent, the web practices that Godel describes. Posting photographs and stories of the stillbirth integrates the event into a person’s (Instagram) biography. The content is visible to the person’s followers, who can leave comments expressing their sympathy. One could, like Godel, conduct a visual study of the images, placing them in lineage with practices of memorial photography.

My interest lies, however, with the hashtag practices emerging around stillbirth and grief. The first recurring practice is the use of hashtag campaigns to express grief. In these cases, the acknowledgment of grief is not voiced by hyperlinking or inscribed in guestbook entries. Instead, on Instagram, hashtag campaigns organize networks of related content and make grief, in Zappavigna’s terminology, “ambient.”

Hashtag campaigns are initiatives “usually meant to gain social media attention, to create engagement, or drive traffic for a specific topic, product or idea” (“The Importance of” 2019, para. 2). Social media users participate in them by including a pre-determined hashtag into their own content. For example, the Ice Bucket Challenge was a successful campaign for raising awareness about ALS. People poured cold water on themselves and shared the documentation online, using the hashtag ‘ice bucket challenge.’ By including the hashtag, they contributed to and affiliated themselves with the theme and values of the campaign.

Participation in such campaigns is, likewise, a matter of clicking on the hashtag and navigating through the content that other users have created and that also includes it. These practices lead Instagram users to develop an ambient awareness about the theme of the campaign and the participants - or, put differently, a peripheral knowledge about their environment and networks of likeminded people. While fragmented, this form of knowing can lead “to a coherent representation of social others” (Levordashka & Utz, 2016, p.1).

Scholars have employed the term ‘ambient’ in various media contexts. For example, the notion of ‘ambient journalism’ describes how “lightweight and always-on systems are enabling citizens to maintain a mental model of news and events around them” (Hermida, 2010, p.297). A sense of ambient awareness has also been observed in online debates about the pervasiveness of sexual abuse and the suffering of victims, among those following (and participating in) the #metoo
movement. In scenarios like the #metoo discussion, participation in hashtag campaigns can lead “an ambient audience to align with their bonds” (Zappavigna, 2011, p.801).

Ambient, I argue, is also an appropriate term to describe how Instagram users who have had a stillbirth share their grief and learn about the grief of others. The hashtag campaign ‘Capture Your Grief’ (in the cluster Rituals) neatly demonstrates why. This campaign, launched by blogger Carly Marie, encourages people to complete a list of daily grief-related challenges and to share the documentation using the hashtag ‘capture your grief’. One challenge is sharing a photo of yourself before the loss and then taking an ‘after loss self-portrait.’ On day fifteen of the campaign, people were invited to “light a candle at 7 pm to help create a continuous wave of light around the world for 24 hours” (Marie, 2016, para.18). According to Marie, the campaign “is a mindful healing project for anyone who is grieving the death of a baby or child of any age or gestation child” (2016, para.1).

Hashtag-enabled rituals such as these are not necessarily occurring at the same time or space. Nevertheless, because the posts include the same hashtags, Instagram aggregates them and allows users to discover and follow the content as it accumulates over time. For example, querying Instagram for the hashtag ‘capture your grief’ returns an (at the time that this book was written) ongoing series of images of homemade altars, pictures taken during the earlier months in the pregnancy, and crafts featuring the names of the diseased infant. Examples of these post can be seen in Figure 4.

Figure 4: Capture your Grief 2017. Querying Instagram for the hashtag ‘capture your grief’ returns posts associated with the hashtag campaign. These posts include photographs of homemade altars, pictures women took during the earlier months of the pregnancy, and crafts featuring the names of diseased infant. Source: Instagram.

Hashtag campaigns about stillbirth and grief acquire a more political tone in connection with issue days. For example, as can be seen in Figure 5, in the cluster
*Motherhood in Loss*, three sub-clusters, framed in blue, gravitate around the hashtag ‘pregnancy loss awareness.’ In these sub-clusters, one finds the hashtags ‘grieving mom’ and ‘October 15.’ October 15 is International Pregnancy and Infant Loss Remembrance Day. These issue days (and its corresponding hashtag) become an opportunity to make individual grief known and educate people about common missteps.

As said, people frequently offer support in ways that deny the importance of a bereaved parent’s loss and grief. About this problem, one Instagram user writes in a post: “to the women who mean well, to those who are trying to help the hurt [...] may I ask in all sincerity and without any malice, please never say the phrase don’t worry you will get pregnant again.” This same person then explains that it is not possible to guarantee that someone will get pregnant again or that the next baby will be full term. Her post includes the hashtags ‘moms of angels,’ ‘one in four,’ ‘angel parents,’ ‘stillbirth,’ ‘miscarriage matters,’ ‘see you in heaven,’ and ‘October 15.’ Another woman, in a different post, debunks the equally hurtful assumption that living children automatically remove the grief derived from previous losses. Her post reads: “I find comfort in the babies I do have but I still grieve the ones I do not.” She includes the hashtags ‘one in four,’ ‘angel parents,’ ‘stillbirth,’ ‘miscarriage awareness,’ and ‘October 15.’

**Figure 5: Motherhood in loss.** In the graph three sub-clusters, framed in blue, gravitate around the hashtag ‘pregnancy loss awareness’, which has the largest number of edges. In the sub-clusters, there are hashtags such as ‘one in four,’ ‘angel parents,’ ‘miscarriage matters,’ and ‘October 15,’ which address parental subjectivity and contest the assumption that grief derived from stillbirth and pregnancy loss is inconsequential.
There are also in the cluster *Motherhood in Loss* hashtags that affirm parental subjectivity, that is, the right to call oneself a mother. Two of these hashtags are ‘angel babies’ and ‘motherhood.’ The iconography of angels is widespread in the discourse of perinatal loss. Indeed, it “is one of the most frequent responses to the realness problem of pregnancy loss and the question of how to visibly represent a lost child” (Keane, 2009, p.160). Close to these two hashtags, on the left-upper and right-lower corners of the graph (again, Figure 5), are hashtags such as ‘stillborn but still loved’, ‘still a mother’, ‘still birth still loved’, and ‘no more taboo.’ These hashtag campaigns help parents position themselves against the perceived notion that stillborn children do not matter and are not missed, thus making their grief known and affirmed. This is one of the cases in which hashtags are worn like a “coat of arms” (Yang, Sun, Zhang & Mei, 2012). Yang and her co-authors use this notion to describe how hashtags can work as “a unique indicator of both the topic of the content and the membership of a community” (Yang, Sun, Zhang & Mei, 2012, p.262).

The hashtags ‘Mother’s Day,’ ‘Mother's Day 2017,’ ‘International Bereaved Mother’s Day’ and ‘Bereaved Mother’s Day’ are also present in the cluster *Motherhood in Loss*, as well as in the clusters *Identity* and *Rituals*. While it might be too schematic to describe Mother’s Day and Bereaved Mother’s Day as program and anti-program, the activity occurring on those days does constitute an example of how women who grieve pregnancy loss and stillbirth use hashtags to reclaim visibility for their experiences.

For grieving women, posting and tagging content during Mother’s Day is a way to participate and reclaim the day. One Instagram user writes, for example, “Ah Mother’s Day. Such an awesome day right? Well, for some momma's Mother’s Day isn’t a kind day.” She also describes how her daughter made her a "mom in the physical sense." However, she has spent the past five years “dreading and wishing for that innocent day that is loved by so many to just be over.” Regardless of her feelings, she asks other people to please include in their celebrations women who are affected by miscarriage, stillbirth, and child loss. Her post includes the hashtags: ‘Mothers’ Day,’ ‘grief,’ ‘pregnancy after loss,’ and ‘rainbow baby.’

Other Instagram users echo this call for inclusion. One of these user writes, “happy Mother's Day to every kind of beautiful mother out there. Some of us don’t have our babies to hold in our arms, but we’re still mothers.” Similarly, another person explains: “I became a mother multiple times before I held a baby in my arms [...] I think about all my children all the time.” The posts include the hashtags ‘my babies,’ ‘stillbirth,’ ‘stillborn,’ ‘infant loss,’ ‘baby loss,’ ‘miscarriage,’ ‘multiple losses,’ ‘life goes on,’ ‘International Bereaved Mother’s Day,’ ‘may 7th,’ ‘Mother’s Day,’ and ‘pregnancy loss awareness’. This type of post often includes photos at grave-sites and Mother’s Day cards.
The content that I have so far referenced is posted on personal Instagram accounts and is visibly to the account owner’s followers and to the people following the hashtags. In addition to these personal accounts, one finds accounts which are dedicated to amplifying and aggregating individual messages and grief. The account @ihadamiscarriage is a case in point. This account is managed by a psychologist specializing in maternal mental health. She created the hashtag campaign ‘I had a miscarriage’ and has 37.1k followers. Another example is @Stillbornstillmatters, an account that works towards breaking taboos around stillbirth. Finally, @graysonproject_birthdaywishes is dedicated to celebrating ‘angel’ birthdays.

Loss as a #journey

The same person who has had stillbirth may have also had miscarriages. People undergoing fertility treatments will, likely, experience multiple events of pregnancy loss – stillbirth may happen more than once. Maintaining hope for a live birth is necessary, however; there are no guarantees. In the words of Pamela Meredith, expert on occupational therapy, “the consequences of previous perinatal loss may extend to a subsequent pregnancy. Women who become pregnant again may doubt their ability to maintain a successful pregnancy, and fear a reoccurrence of perinatal loss” (Meredith et. al., 2017, para. 9).

On Instagram, women speak about the reappearance of these events (e.g., miscarriage, stillbirth) and frame reproductive loss and birth, accordingly, as journeys. Some posts have images and captions in which the person explicitly discusses the recurrence of events and also includes hashtags that express the metaphor of the journey (e.g., the hashtag ‘infertility journey’). In other occasions, neither the caption or image are explicit about the person’s multiple losses. It is only because they include, in the same post, numerous hashtags that reference the different events—a sort of running list—that a sense of journeying is communicated. In these cases, hashtags function as “both metadata and metadiscourse” (Zappavigna, 2018, p.2). Below, I illustrate these journey-making hashtag practices.

The meeting of events such as stillbirth, miscarriage, and infertility (and the need to speak about them together) is perceptible in the cluster Pregnancy Loss and Hope. As can be seen in Figure 6, two journeys come together, each forming a sub-cluster. In the first sub-cluster (red inset) the hashtag ‘pregnancy loss journey’ cooccurs with ‘surviving stillbirth,’ ‘miscarriage,’ and ‘medically terminated.’ The second journey (blue inset) is about infertility and trying to conceive. Hashtags in this sub-cluster include ‘infertility journey,’ ‘infertility,’ ‘IVF warriors,’ ‘IVF journey,’ ‘TTC journey,’ and ‘infertility sucks.’ The abbreviation IVF stands for in vitro fertilization, the medical procedure whereby an egg is fertilized by sperm.
outside the body. TTC stands for ‘trying to conceive.’ Pregnancy loss journeys and infertility journeys are connected by the hashtag ‘hope.’

Figure 6: Hope and pregnancy loss. In the graph two types of hashtags come together. In the red inset is a sub-cluster of hashtags about pregnancy loss journeys and the identity of the ‘angel mommy.’ In the blue inset, are hashtags referring to infertility journeys.

In one of the posts that belongs to this cluster, a woman writes about her recent stillbirth, which is one of the many losses she has experienced. In the post, we see her holding the hand of her baby, who was stillborn. The caption reads: “I honestly never thought I would have to do an update like this again. But here I am.” She includes the hashtags ‘stillborn still loved,’ ‘stillbirth,’ ‘pregnancy loss,’ ‘supposed to be our rainbow baby,’ ‘sorrow,’ and ‘second stillbirth.’

Figure 7 is another example of a person highlighting the recurrence of loss and journeys and using hashtags to support this information. The post is a meme with the text “don’t be ashamed of your story. It will inspire others.” The caption states: “Your struggle and your journey make you who you are. Never be afraid to share it. You never know when someone is experiencing something similar. Your story could give them hope and inspire them.” It includes the hashtags ‘pregnancy journey,’ ‘infertility journey,’ ‘infant loss,’ ‘stillbirth,’ and ‘miscarriage.’ Here it is worth noting that without these hashtags, the connection and meaning of the meme in relation to pregnancy loss and its stigma could not be inferred.
In another cluster, *Motherhood After Loss*, two other events come together, forming a different journey: pregnancy loss and (potential) rainbow babies. The cluster, as seen in Figure 8, unites hashtags for speaking about ‘typical’ pregnancies with hashtags specific to pregnancy loss. Typical hashtags include, for example, ‘pregnancy journey,’ ‘second trimester,’ and ‘third trimester.’ These hashtags “guide viewing through the temporality of pregnancy [...] which invites searches from people interested in this particular content (presumably other pregnant women)” (Tiidenberg, 2015, p.1752). Alongside these ‘typical’ hashtags are the hashtags ‘pregnancy after loss,’ ‘parenting after loss,’ ‘rainbow baby,’ ‘stillbirth,’ and ‘always be someone missing’.

As part of *Motherhood After Loss*, one finds a posted photograph that follows the visual conventions of a typical pregnancy selfie, the woman poses in front of a mirror with a hand placed on the stomach. The author of this post writes, “I have my check and scan at the obstetrician [...] This time I actually don’t feel nervous (yet) [...] everyone expects me to get scared [...] when I reach the point in the pregnancy where [he] died.” The author is referencing her previous stillbirth and reflects on how the experience frames her pregnancy as well as how other perceive it (e.g., the expectation of fear). The post also includes the hashtags ‘pregnancy loss journey,’ ‘pregnancy,’ and ‘pregnancy after loss.’
In the cluster *Motherhood After Loss* one also finds hashtags that thicken and modify the narrative that the photos tell us. The post below, Figure 9, is another pregnancy selfie. The caption reads, “36 weeks. Seven days left. We can do this.” The author includes the hashtags ‘pregnancy after loss,’ ‘rainbow baby,’ ‘stillbirth,’ ‘child loss,’ ‘stillborn,’ ‘infertility,’ ‘baby girl,’ and ‘born still but still born.’ The presence of these hashtags adds context and alters the meaning of the image significantly. They lead one to infer — a conclusion that is confirmed by reading additional posts by the same author — that she has experienced a stillbirth and is, now, expecting her rainbow baby. In the same post, the hashtag ‘born still but still born’ also tell us that the previous pregnancy mattered. In these cases, hashtags such as ‘infertility,’ ‘stillbirth,’ and ‘born still but still born’ do not merely reiterate information that can also be found elsewhere in the accounts: they offer and “aid,” in Zappavigna’s words, “pragmatic inference” (Zappavigna, 2018, 44-45). In the context of stillbirth, love is not automatically inferred but, rather, needs to be re-affirmed. These are cases where hashtags more explicitly become storytelling devices.
The meaning of the pregnancy selfie is altered by the inclusion of hashtags such as ‘pregnancy after loss,’ ‘rainbow baby,’ ‘stillbirth.’ I have edited the image and obscure any person information to protect the privacy of the author.

As the examples which I have offered in this section illustrate, Instagram is a space to discuss and share personal histories about overlapping journeys and anxieties. In the posts I described earlier, the tropes of the ‘journey’ and a shared sisterhood resonate in the hashtags. However, the same concepts of the journey and sisterhood – and this is a crucial point – are not always present in the captions or in the images. The diversity of hashtags helps storytellers share complex identities that acknowledge loss as recurrent and render themselves visible to women in different, yet related, circumstances.

Reaching bereaved #mothers through promotional hashtags

In the introduction of this chapter I discussed online commercial practices around pregnancy. These included mommy influencers prompting products and brands and services targeting pregnant women. A promotional post of this kind, typically, uses hashtags that are unique to a brand (e.g., the name of the brand) along with other more generic baby-related terms. An example: to promote baby clothing, a brand will make a hashtag from its own name and include it alongside hashtags such as ‘mom life’ or ‘pregnant.’ We also witness commercial hashtag usage among Instagram users who share the products that they buy with their networks. For instance, a mom-to-be might post about the outfits she just bought and tag the brand. Tiidenberg and Byam (2017) relate this type of activity to the discourse of consumerist pregnancy. Their conclusions suggest that doing pregnancy well involves buying the right products. Ergo, a “caring mother must be a well-informed and discerning consumer, shopping for the safest pram [and] the most natural food” (Keane, 2009, p.155).
The third and last practice I discuss involves charities and brands using loss-related hashtags to target bereaved mothers. Indeed, throughout the ‘stillbirth’ network, and especially in clusters Arts and Charity and Inspiration we also find posts created by brands, makers, and organizations. These actors address bereaved mothers as consumers and use the (now familiar) loss-related hashtags, but for promotional ends. Real Woman Real Journey (RWRJ) is a good example. This network of female professionals is committed to women’s wellness. RWRJ uses Instagram to promote their events. In one of their posts, they thank their guest speaker and author Alexis Marie Chute. Her book Expecting Sunshine (2017) “chronicles the anticipation and anxiety of expecting a baby while still grieving for the child that came before” (Chute, 2019). The post reads: “Get your copy of Expecting Sunshine!” It includes the hashtags ‘expecting sunshine,’ ‘art heals,’ ‘PTSD recovery,’ ‘rainbow baby,’ ‘angel baby,’ ‘pregnancy loss,’ and ‘stillborn’. A woman searching for content related about stillbirth using any of these hashtags might, by default, encounter also Chute’s book.

The RWRJ post is no isolated case. The clothing brand Loved by Hannah And Eli offers a mama bear t-shirt. In a promotional post, see figure 10, they say: “Tomorrow at 7 am PST is the next release of the #rainbowmamabear items!!!” The post includes the hashtags: ‘loved by Hannah And Eli,’ ‘mama bear shirt,’ ‘bereaved mother,’ ‘miscarriage awareness,’ ‘rainbow mom,’ ‘infertility,’ and ‘bereavement gift.’

Figure 10: Mama bear T-shirt. The brand Loved by Hannah And Eli uses hashtags related to pregnancy loss to market its ‘mama bear’ T-shirt.

Similar hashtag strategies are used by crafters who sell specialized keepsakes, such as jewellery, drawings, and dolls. The artist behind the account @athreadrunstrruit, for instance, “creates memorial gifts & keepsake dolls to remember special people & occasions.” She uses Instagram to promote an angel baby figurine (Figure 11). The caption under the image reads: “Sweet sleeping angel. I just love how all the colors.” Hashtags include ‘baby loss,’ ‘pregnancy
loss,’ ‘infant loss,’ ‘miscarriage awareness,’ ‘miscarriage,’ ‘stillbirth,’ ‘life after loss,’ ‘grieving mother,’ and ‘my baby has swings.’

Figure 11: Angel baby figurine. The account @athreadrunsthruit uses hashtags related to pregnancy loss to promote a memorial figurine, an ‘angel baby’.

In addition to craft makers, doulas and grief counsellors also use hashtags to reach grieving mothers. Themed hashtags circulate, finally, in posts by organizations that help women cope with loss. An example is Madison’s Closet Shop, an online clothing platform that aims “comforting and clothing our sisters in perinatal loss.” After having a stillbirth, the creator could not bear to wear her maternity clothes. She felt unable to shop for herself. “It wasn’t because I couldn’t afford to buy a few things to wear,” she clarifies. “It was because I couldn’t face clothing a body that I hated, a body I felt failed me” (“Madison’s Closet Shop”, 2019). The clothing platform runs on donations so that women can “order clothing free of charge from the comfort and safety of their homes” (“Madison’s Closet Shop”, 2019). A post from them typically includes the hashtag ‘Madison’s closet’ together with pregnancy loss terms and recruiting hashtags such as ‘volunteers.’

The examples that I have discuss in this section reinforce that there is an online consumer culture around pregnancy loss and motherhood in loss. Brands, makers, and charities are creating a network of objects that lend materiality to the often invisible experiences of stillbirth and pregnancy loss. The existence of these products appears to be received well by the members of in this pregnancy loss communities. What heightens their appeal is that a great deal of the entrepreneurial initiatives were created by women who themselves experienced stillbirth and similar experiences. These commercial enterprises also become a way to reach out to others.

Will, just like pregnancy itself, grieving well also become a matter of buying the right things? The possibility of an online consumerist culture around pregnancy-related loss is worth exploring in further detail. So are the potential dangers of such a culture. There is a risk, of course, that targeting grieving communities
might be exploitative at the hands of unlicensed healers, or damaging, given its inevitable share of misinformation.

Tagged bodies, wounded healers, and lifespans

In this chapter, I discussed how women use Instagram to post and tag content about their experiences with stillbirth and other forms of pregnancy loss. Tagging is a pervasive activity on social media. Tags function as metadata that supports the classification of online content, navigation, and the creation of folksonomies. Tagging also supports meaning-making, bonding, and the articulation of networked publics. The practice of tagging has, in fact, become a way for social media users to express themselves and engage in politics.

Tagging (and all that it affords) is not secondary but central to contemporary online illness storytelling. The stories of tagged bodies, which is the concept I put forward, are stories about illness in which tagging is key both for how the story is told and to accomplish the goals aimed for by storytelling. In these illness stories tags work as metadata with affordances and semiotic technology that helps make meaning.

An investigation of stillbirth on Instagram, as well as of other illness stories, must therefore understand and account for tagging. To study the stories of tagged bodies, I have put forward co-hashtag network analysis, which combines the analysis of the topography of a network with the close reading of content and hashtags.

The results of my analysis I organized as three hashtag practices. The first is the participation of bereaved parents in hashtag campaigns that make grief ‘ambient,’ to speak with Zappavigna concept (2018). Through these campaigns, individual expressions of grief and memorialization – on Mother’s Day, for example – are aggregated and rendered visible to other users in the platform. The second practice involves using hashtags to create meaning and speak about loss and (in)fertility as a journey. The concepts of quests and journeys is important in illness narrative and specially release in the context of pregnancy loss. While the social expectation is that the grief derived from experiences such as miscarriages be overcome quickly or quietly (Brierley-Jones et al., 2015), on Instagram, women discuss present and past events together, creating a form of narrative coherence. Furthermore, Instagram connects bereaved parents with charities, brands, and makers who target them as consumers. These entrepreneurs – this is the third practice that I discern – employ promotional tagging to become visible and align with existing loss publics.

I see these posting and tagging activities as enabling the circulation of a coded-language and practices that make visible stillbirth and pregnancy loss and reframe
them as meaningful storytelling practices rather than isolated instances. Tagging also supports goals of raising awareness, breaking taboos, and reaching out to others in similar consequences. In light of these findings, I see an opportunity to update and expand the concept of wounded healing.

As I mentioned earlier, Arthur Frank (2013) employs the term ‘wounded healing’ to describe how people who are severely and chronically ill find goals beyond cure and meaning outside established frameworks; and how, in doing so, they embrace active roles in their communities. Personal storytelling is a vital tool for wounded healing. In fact, wounded healing is, for Frank, the work of “communicative bodies,” who share intimate details about themselves with the aim “to touch others and perhaps to make a difference in the unfolding of their stories” (2013, p.127). These narratives are not the stories of people whose suffering has ended. Instead, they are stories about finding meaning under hardship. By telling these stories people aim to convey to others the possibility that a meaningful life is possible and frame their suffering as a relevant, even against social conventions. As Frank as phrased storytelling is tool when “society is suppressing a truth about suffering, and that truth must be told” (Frank, 2013, p.121). Ultimately, “as wounded people, they may be cared for, but as storytellers, they care for others” (Frank, 2013, p. xx).

In developing his concept of ‘wounded healing,’ Frank built on literature written by patients. By applying the concept to social media activity around stillbirth, I also offer an investigation of wounded healing and communicative bodies as medium-specific and of social media affordances as conducive to wounded-healing practices. In other words, I argue that by tagging their stories and, thus, making themselves searchable and networked on social media, bereaved women work towards breaking silences and taboos around stillbirth, creating networks, and helping others. In doing so, they conduct a slightly different type of wounded healing than that outlined in Frank’s research. On social media, Frank’s ‘communicative body’ becomes a tagged body, and wounded healing is socio-technical and platform-specific.

Approaching tagging practices through the case study of stillbirth and Frank’s ideas about illness storytelling has enabled me to see familiar devices –hashtags – from a new perspective. Hashtagging also prompted me to inquire into how wounded healing may occur online and with digitally native practices, thus updating the question: what do illness stories do? The stories of tagged bodies challenge, at least to some extent, the discourse of frivolity and of passivity that surrounds tagging. As Zappavigna puts is, “hashtags have been subject to criticism and offered as evidence of the narcissistic self-involvement of digital practices” (Zappavigna, 2018 p. 5). I agree with Zappavigna that this critical-only reading of hashtagging is reductionist. In the context of stillbirth, to make oneself searchable
and aggregatable acquires an ethical dimension of responsibility and risk-taking, which is described as valuable by those involved.

This ethics of responsibility and risk is, perhaps, best felt during moments in which the interests of different social media users come into conflict. Some stillbirth storytellers have gone ‘viral’ and found themselves the object of online scrutiny. An example: The Daily Mail wrote about Morgan, who went ‘viral’ after sharing “a series of heartbreaking photos on Facebook that show her and her husband ... cradling [their daughter] who died in utero at 40 weeks” (James, 2015, para. 2.). While reporters sympathized with Morgan, her social media posting was flagged by other users because of its alleged offensiveness. Emily and Richard Staley also shared a photoshoot with their stillborn baby. The Huffington Post asked Emily about her motivations for speaking up and risking pushback. Staley said “that she hopes her photography can help break down the silence surrounding stillbirths” (Bologna, 2014, para. 1). Similarly, Jackson shared images of her stillborn baby on Instagram. She argued: “my baby had every right to be shown off by his mother just like a baby who was living” (Ritschel 2018, para. 1). While it is suggested that the fathers were also involved in posting, the women who used their personal accounts to do so become the subject of critique.

The presence of stories like this on social media will continue to reinvigorate discussion about the sequestration of experiences of illness and death – mediated lifespans – of which stillbirth is but one example. As we speak, users are performing an active platform politics around birth, grief, and death. What aspects and stages of life are appropriate for mediation? Leaver and Highfield (2020), for example, work to redeem funeral selfies, which have caused their own share of scandals in the media. However, the funeral selfie, academic studies find rather than a frivolous act, is a form of self-mediation that has become part of new rituals to deal with death. A live birth and happy childhood (with the exclusion, perhaps, of excessive ‘sharenting’) rank as uncontested food for social media. Stillbirth and motherhood loss appear to be less uncontroversial. Just as Leaver and Highfield argue for funeral selfies, so I hope that this chapter has made a case for the value of social media communication about stillbirth and pregnancy loss.
Chapter 4
Crowdfunding and the Ranked Body
In chapter two, I discussed how Sophia Gall and Daniel Toms vlogged about cancer and the end of life. Their popularity on YouTube became a source of agency and entrepreneurialism as well as pressure. In chapter three, I studied how women use Instagram to talk about stillbirth. On the platform, tagging makes stories about loss networked and search-able and sustains online mourning rituals. I called these two types of illness stories, respectively, stories of popular bodies and tagged bodies.

In this fourth chapter, I study medical crowdfunding on GoFundMe.com. Crowdfunding is the practice of funding projects or ventures by raising small amounts of money from a large number of people. Medical crowdfunding applies this principle to financing personal medical care.

The California-based company GoFundMe describes itself as the leader in this category of crowdfunding. The site hosts more than 250,000 health-related campaigns per year ("Medical Fundraising" 2019). Since its establishment in 2010, GoFundMe has been joined by rivals CrowdRise and YouCaring, and with time, medical crowdfunding is gradually standardizing (Gonzalez, 2018).

People appeal to potential crowdfunding donors by telling stories about their illnesses. On GoFundMe, this process begins with opening a campaign, which serves both as a template and homepage. Then, one sets a monetary goal and explains the dire health and financial conditions that led one to crowdfund. To reach donors, it is imperative to share the campaign with friends and family and their extended (online) networks.

Media researcher Laura Berliner and medical anthropologist Nora Kenworthy studied a “randomized sample of 200 [GoFundMe] campaigns between March and September of 2016” (Berliner & Kenworthy, 2017, p.235). They found that “90% of campaigns did not meet their goal, and on average netted just over 40% of their goal” (Berliner & Kenworthy, 2017, p.236). They also learned that campaigns that present urgent yet discrete “needs (such as an MRI or drug treatment) that promise a possible solution” (Berliner & Kenworthy, 2017, p.240) are more marketable and compelling. In contrast, campaigns perform worse when the financial need is extensive and indicative of a more dire socio-economic situation extending beyond the illness.

By “virtue of being more needy,” Berliner and Kenworthy conclude, people “may appear less deserving [...] To wit, the more generalized one's distress or the more complex one's needs, the more difficult they become to represent” (2017, p.240). Said differently, to prosper in medical crowdfunding, a person needs to tell the right type of illness story. Berliner and Kenworthy describe medical crowdfunding,
fittingly, as yielding “a moral economy of deservingness [...] constructed, reinforced, and appealed to throughout” sites like GoFundMe (2017, p.236).

The issue of deservingness is long-standing in healthcare. It refers to how a person’s character and behavior affect the perception of their right to access quality healthcare. Studies conclude that, in the United States, for example, people tend “to oppose welfare benefits when the need reflects a lack of motivation (i.e., ‘laziness’) but support benefits when the need is caused by random events beyond the individual’s control (i.e., ‘bad luck’)” (Jensen & Petersen, 2016, p.71). Likewise, people who are overweight, poor, people of color, members of LGTB communities, and people with stigmatized conditions (e.g., drug addiction or lung cancer) report facing bias and being recipients of low-quality care (Berliner & Kenworthy, 2017; Snyder, 2016). Medical crowdfunding, Berliner and Kenworthy conclude, recreates such issues and “reinforces a hyper-individualized system of choosing who is and who is not deserving” (Berliner and Kenworthy, 2017, p.241).

In this chapter, I, too, conduct an inquiry on storytelling in medical crowdfunding and the need to perform deservingness. However, I do not focus on individual campaigns, as Berliner and Kenworthy have done. Instead, I explore these questions through an analysis of GoFundMe’s USA website. First, I critique the storytelling and marketing advice that GoFundMe offers users through its website. As I illustrate, the site encourages one-sided attention for “restitution plots” (Frank, 2013), whose protagonists are survivors, that is, people who are gravely ill but are willing to fight and, most importantly, are deserving of healing and financing. This one-sidedness potentially excludes people with less marketable conditions that cannot be narrated in the language of cure.

Next, I study the different ways in which GoFundMe has ranked campaigns on its homepage over the past ten years. An example: when visiting GoFundMe’s medical page today\(^\text{20}\), one finds a list of campaigns that are ‘trending.’ Ten years ago, campaigns were organized according to recent donations. I see the algorithms and their criteria (e.g., trending and newness) as cultural objects that construct, reinforce, and appeal ideas of deservingness. That is, they frame how the suffering of others is known and valued. In this second step, I employ as a technique a ‘website biography.’ Richard Rogers uses this term to describe research that traces changes on a website’s content and infrastructures (2019, p.100). To support this research method, I work with the Internet Archive’s Wayback Machine, which allows navigating archived versions of websites, including, in this case, www.gofundme.com.

Each type of illness story I have proposed in this book foregrounds specific socio-technical aspects and methods of social media. The stories of popular bodies on

\(^\text{20}\) Information recorded on 14 March 2020
YouTube are illness stories told through the vernaculars of micro-celebrity and popularity metrics. The stories of tagged bodies are illness stories in which tagging is essential for communicating the illness experience. Now, I refer to the illness stories told through crowdfunding platforms and ranked by algorithms as the stories of ranked bodies.

A critique of medical crowdfunding and ranked bodies is timely. The practice is now widespread in, for instance, the United States, where a significant part of the population is under-insured and left with large bills and out-of-pocket costs. In this scenario, crowdfunding is framed as a means to compensate for lack of accessibility and avoid medical bankruptcy. In fact, in the United States, there is a move towards the normalization “of the impression that crowdfunding can be a substitute for broad healthcare reform” (Hiltzik, 2017, para. 6). My work joins emerging academic and journalistic literature (Scott, 2014; Snyder et al., 2017; Berliner & Kenworthy, 2017; Paulus & Roberts, 2017; Petersen, 2017) that critiques this normalization and the dynamics introduced by medical crowdfunding.

In addition to the United States, GoFundMe now supports campaigning in Australia, Canada, Austria, Luxembourg, The Netherlands, Belgium, and the United Kingdom, amongst other countries (“Supported Countries”, 2019). In some of these locations, medical crowdfunding has grown significantly. For example, the Dutch newspaper De Volkskrant reported a six-fold in this type of crowdfunding campaigns in the Netherlands since 2015 (van Gestel, 2019). The funds collected are destined for procedures that Dutch health insurance companies do not cover. Similarly, British people use crowdfunding to pay “for essential treatment in a desperate, ‘Dickensian’ attempt to get around NHS shortfalls” (Kale, 2019, para. 1). Amongst the procedures are “amputations that the NHS deems unnecessary” (Lay, 2017, para.1).

Most academic literature, including the sources used in this chapter, addresses the American context (Hiskes, 2017; Kneese, 2018). However, there are also academic studies discussing crowdfunding in Canada (van Duynhoven et al., 2019), China (Jin, 2019), and in Europe (Bassani, Marinelli & Vismara, 2018).

GoFundMe’s plots and advice for telling stories.

GoFundMe is explicit about the importance of telling ‘good’ stories to achieve the desired effect: funding. Through its website, GoFundMe offers users campaign templates with instructions, examples of successful stories, and guidelines that describe how to write and market their illnesses and themselves. These materials, as I illustrate in this first part of my analysis, promote restitution plots and survivor-like notions in ways that prove problematic.
The term ‘plot’ refers to the main events in a narrative and the relationship between these events. The description of the plot is what usually answers the question: what is the story about? As I discussed in the introduction of this book, researchers use similarities in plots to group illness stories. Two examples are "restitution stories" (Frank, 2013) and "didactic pathographies" (Hawkins, 1999); these are recurrent stories about a patient's efforts to become healthy.

In restitution stories, the patient states: “Yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again” (Frank, 2013, p.77). In these stories, future health is envisioned as the outcome of medical treatment. Thus, people render illness into a coherent experience, leaning on Western visions on medicine, regimes, and monitoring. The stories involve sick people cooperating “with physicians and practitioners by assimilating the biomedical discourse” (Tosás, 2019, p.256) and assuming the position of a “restorable body” (Frank, 2013, p.84).

A mainstream example of the restorable body is the cancer patient as ‘survivor.’ This particular idea of restitution has helped patients and those around them envision the work of ‘getting better.’ For instance, people with cancer are encouraged to distance themselves from victimhood and shame and embrace "optimism, personal empowerment, and the ‘survivor’ as an identity category" (Sulik, 2011, p.30). Survivorship, as Orgad (2009) presents in her genealogy of the term, has, in fact, become a desirable identity that people work towards obtaining. That is to say, “one becomes a survivor” (Orgad, 2009, p.150 [emphasis mine])

The survivor is “a self-responsible individual with a considerable degree of agency, who emerges from a struggle involving some kind of suffering, through a process of self-exploration and styles of self-management” (Orgad, 2009, p.150). This agency, in the context of serious illness, can involve, more concretely, working towards a cure and, ideally, obtaining it. Thus, patients are framed as ‘cancer warriors’ who, in addition to being devoted to treatment, are socially active, and engaged in medical consumerism.

Jurecic (2011) finds that the restoration plot and survivor rhetoric emerge even in the face of unfavorable odds. She uses David Rieff’s account of the death of his mother, Susan Sontag, to prove this point. Rieff described Sontag, at the time a cancer patient, as someone who “rejects the statistical prognosis, resists uncertainty, and refuses a narrative that does not end in survival” (Jurecic, 2011, p.25). His mother was “certain that she can fight the odds, which are entirely against her, as long as she is willing to suffer” (Jurecic, p.24-25). To survive, in this context, means taking action by enduring pain and, then, working towards health by any means necessary.

The attitude of survivorship can come to frame a wide range of experiences on the illness continuum, including the many psychological, financial, spiritual, and
social challenges of "living with, through, and beyond a cancer diagnosis" (‘The NCCS Definition’, 2014, para. 2). In fact, survivorship is marketed as a way of life, making the work of restitution clinical but also cultural and personal. For example, television news programs have a preference for positive stories “in which the sick are made good-as-new” (Wagner, 2000, p.16). Also, the restitution narrative is pervasive in healthcare communication and marketing. Vater et al. (2014) found, for instance, that the advertisements created by cancer centers in the United States borrowed heavily from ideas of “hope for survival, promoted innovative treatment advances, and used language about fighting cancer” (p.2).

One of these advertisements reads: “I used to think that you had to go to NYC for anything serious but after my experience, I don’t know why anyone would go anywhere but the Littman Cancer Center. They saved my life” (Vater et al., 2014, p.6). Vater et al. argue that in this type of communication “fear appeals persuade an audience by presenting negative consequences (e.g., the progression of cancer or death) and by subsequently providing a solution to the undesirable outcome (e.g., receiving cancer treatment at a specific location)” (2014, p.7). One may say that these cancer centers employ the language of restitution (trust in medicine) and survivorship (personal responsibility and choice) to advertise themselves as prospective participants in people’s illness stories. In for-profit medical systems, this same capacity for restitution and survival is billed and made into a commodity. The person who is sick is faced with calculations about the cost of treatment, insurance premiums, and loss of wages.

Survivor cultures and cultures of cure have been critiqued in terms of their limits, biases, commercialism, and normative character (Sulik, 2011; Lerner, 2003; King, 2008; DeShazer, 2013; Clare, 2017). For instance, breast cancer patients might report not feeling comfortable with the label ‘survivor’ if the cancer was caught early or they did not require a mastectomy. In addition, people reject the idealization of breast cancer survivors as “feminine, deserving and devoted to a medical cure” (Kaiser, 2008, p.3) and “implacably optimistic” (Ehrenreich, 2001, para. 31). Such a narrow emphasis on warriors, optimism, and cures leaves little space for bodies and selves that cannot be fully restituted. Metastasized cancer patients, for example, describe feeling disconnected from survivor culture: “When we lose, that means we didn't fight hard enough” (Wolinsky, 2019, para. 34). Informing these critiques are, indeed, notions of deservingness. A sick person is expected to behave in certain ways in order to be perceived as deserving of healthcare, but also of the label of survivor.

Patients who resort to medical crowdfunding face ill health and a financial crisis concurrently. Their concern is both about getting better and being able to afford the means to do so. In the midst of these circumstances, crowdfunding sites such as GoFundMe present themselves as a means to perform not health and financial victimhood but rather health and financial survivorship. Put differently,
crowdfunding patients must become the illness warriors of the American healthcare crisis. Crowdfunding becomes a way to practice (not unproblematically) entrepreneurialism and personal responsibility. Tell your story, crowdfund, and fight!

GoFundMe emphasizes the seriousness of financial problems and their pervasiveness in the lives of patients in the United States. The company reports on their website that "40% of Americans can’t afford to spend $400 when faced with an emergency" ("What is Crowdfunding?", 2019, para. 6). In addition, the site claims that “66% of people surveyed said that planning for out-of-pocket costs is both the biggest challenge and most stressful part of healthcare management" ("What is Crowdfunding?", 2019, para. 7). The numbers above suggest that the institutions of medicine can heal the sick body. The one-million-dollar question is: can patients pay for their healing?

Like the cancer centers researched by Vater et al. (2014), crowdfunding sites advertise themselves as prospective actors in the restitution plots of the sick and financially insecure. See, for an example, Figure 12, where an ‘expert crowdfunder’ writes on GoFundMe’s blog: “When you don’t know how to get financial help for out of pocket medical expenses, crowdfunding makes it simple” (Davis, 2018, para. 7). A second set of statistics also reinforces the effectiveness of crowdfunding; according to GoFundMe, their “giving community is more than 50 million strong and has raised more than $5 billion” (“What is Crowdfunding?”, 2019, para. 15).

**Why crowdfund for medical expenses?**

*When people are faced with a sudden medical hardship, they’re often left wondering how to pay for expensive medical treatments and how to avoid medical bankruptcy. People use medical fundraising to raise money for a wide variety of medical-related expenses, from cancer and HIV treatments to surgery costs—and everything in between. Crowdfunding can ease financial stress and allow you to focus on healing.*

- Medical crowdfunding helps spread your story among your family, friends, their friends, and even strangers who want to support you during a difficult time.
- When you don’t know how to get financial help for out of pocket medical expenses, crowdfunding makes it simple.
- Crowdfunding can get you the funds you need fast when you’re facing mounting medical bills. You can begin withdrawing funds as soon as you start receiving donations.
- Crowdfunding can help spread awareness about certain medical conditions and the healthcare system.

**Figure 12: Why crowdfund for medical expenses?** Screenshot from GoFundMe’s blog. The text presents the crowdfunding site as a prospective solution to the problems of people with medical debt and out of pocket costs. Source: https://www.gofundme.com. 2019.

After positioning itself as a service, GoFundMe guides the process of campaigning and the storytelling therein. For example, Figure 13 shows the template that GoFundMe offers people who are starting a medical campaign. According to the instructions on the pop-up window, users must begin by stating in a transparent manner why they need the funds and how they plan to spend them. In other
words, patients are asked to favor disclosure. In fact, according to GoFundMe’s Medical Crowdfunding Guide, “including photos of medical bills may help people fully understand your plight, but you should cover or otherwise remove any sensitive information you don’t want shared” (Davis, 2018, para. 12).

After establishing that their needs are real, urgent, and come with a price tag, people must tell a story that resonates with donors. After all, “donors are more likely to give to campaigns for recipients with whom they sympathize” (Snyder, Mathers & Crooks, 2016, p.28). Accordingly, GoFundMe’s Guide for Fundraising includes a section titled ‘Show Why We Should Care.’ The latter is presented as “the main question in the back of a potential donor’s mind, and the most important question your story should answer” (GoFundMe Team, 2015, para. 30). To make potential donors care, campaigns need to “construct those in need as respectable and worthy of help” (Paulus & Roberts, 2017, p.64). This can be done, for instance, by adding “a few short testimonials from the recipient’s loved one to help show donors the ways the patient has touched other’s lives in meaningful ways and [show] why they deserve a helping hand in a time of need” (You Caring [now GoFundMe], 2017, para. 6).

Being someone who is ‘worthy of help’, in crowdfunding corporate parlance, translates as being hard-working, heroic, and a ‘good’ person — all features that evoke the discourse of survivorship. During an interview, the chief of marketing at YouCaring, reiterated this point and explained how notions of heroism underlined the ideal crowdfunding campaign. She described the fundraising website YouCaring (now a part of GoFundMe) as a company “helping people sell their illness as a ‘narrative of the hero’s journey’” (Marche, 2018, para. 18). The term “narrative” was not chosen randomly. GoFundMe advises patients to model themselves after fictional characters. A post on GoFundMe’s corporate blog, for
example, states that in “books and movies, the audience cares about characters who want something badly, and have (challenging yet surmountable) trouble getting it. People often feel a connection to imperfect characters who are doing their best under extreme circumstances” (GoFundMe Team, 2015, para. 31).

The norm seems to be, in short, that crowdfunding patients should favor and express optimistic feelings. I found similar trends in an earlier study that I conducted using 156 GoFundMe campaigns, all of which aimed to raise funds for cancer patients (Sanchez-Querubín et al., 2016). The campaigns that received more donations were initiated by patients who had published photos of themselves in family settings and while engaged in social activities. In turn, people who published photographs taken in the hospital or used negative language were less likely to meet their funding targets.

Likewise, when involved in crowdfunding, patients, as Berliner and Kenworthy (2017) found, are advised to avoid overwhelming potential donors by making their situation feel too dire, hopeless, or too explicitly about money—even though their situations are often all of the above. A case in point is a BuzzFeed News article by Anne H. Peterson about “who gets funded — and who gets left behind” (2017, para. 1). Peterson presented side-by-side screenshots of two campaign titles offered by GoFundMe as examples. The image caption read: “Which title sounds better? ‘I Need Money!’ or ‘Julie’s Rally Against Cancer?’... The second one, right?” (GoFundMe, as referenced in Petersen, 2017). Petersen remarked about this comparison that the second title situated “Julie” as the hero fighting a good fight; the other de-romanticized the struggle down to its most essential (and truest) form: My need? Money” (2017, para. 14). Not surprisingly, ethnographic studies have also concluded that “campaign narratives walk a careful line between revealing an extremely vulnerable situation—experiencing a health crisis and financial instability—and indicating the worth of the person or people in need” (Paulus & Roberts, 2017, p.66).

In addition to having the right type of illness story, that is, the story of person who is sick, can be cured, and has a ‘good character,’ crowdfunders need media and online marketing literacies. These include writing well, uploading attractive pictures, creating effective hashtags, reaching out to news media, and practicing social media sharing. Indeed, crowdfunders must “harness the power of social media to spread [their] story and get more support” (“How GoFundMe Works”, 2019, para. 11). As seen in Figure 14, campaigns shared on social media allegedly raise up to three times more funds.
Figure 14: Help by sharing. Screenshot of GoFundMe social buttons. These buttons help users share their campaigns on social media sites, which allegedly triples the amount of funds. Source: www.gofundme.com. 2019.

To support social media sharing, GoFundMe offers its users digital devices that operate as “the bridge between social networks and [a] campaign” (“How to Use Your...”, 2019, para. 1). One of these devices is the GoFundMe Link. This unique link helps people share their campaigns online by copying the link or by using social buttons on Twitter and Facebook. The social media platforms through which the campaign link travels have their own devices. Crowdfunders must learn to utilize these, too. For example, according to GoFundMe, you should “create an Instagram account or hashtag, especially for your fundraiser. That way, your supporters can help share your GoFundMe by spreading your hashtag” (“Don’t have Facebook?”, 2019, para. 3). In sum, individual campaigns (and the illness stories they tell) not only need to be attractive, but they also need to be “platform ready” (Helmond, 2015). That is to say, their design needs to be compatible with the ways in which information circulates and user activity is captured on mainstream social-media platforms.

This platform ‘readiness’ also manifests itself in the data that is displayed on a campaign’s page. As seen, below, in Figure 15, on a campaign page, visitors can see the number of donors and followers, the funds that the campaign has collected so far, and the number of times it has been shared. The latter indicates the times a campaign has been re-distributed by people into their own social networks through Facebook, Twitter, WhatsApp, Messenger, Email, and Instagram. The person crowdfunding must be savvy and able to grow these numbers.
With their persistent focus on deservingness, restitution as survivorship, and personal responsibility included that of marketing the story well online, crowdfunding sites obscures issues pertaining to systemic injustice. For example, research shows that “medical crowdfunding websites tend to use language that portrays the need for donations as resulting from an emergency or unforeseeable event rather than due to systemic problems leading to inadequate medical care for campaigners” (Snyder & et al., 2016, p.28). Moreover, the need to perform deservingness has resulted in medical crowdfunding recreating, rather than eliminating, issues of exclusion and bias. Conditions that cannot be narrated (or are not narrated well) in the language of survivorship and restoration are less likely to be funded. In the words of journalist Stephen Marche, “chronic conditions are especially unglamorous, which is why few get results on crowdfunding sites” (2018, para. 26). Likewise, “terminal cases are unappealing to potential funders” and “geriatric care is nearly impossible to fund” (Hiskes, 2017, para. 2). Neither is it possible to fund abortions or euthanasia. Medical crowdfunding has, in short, become a “marketplace of compassion [that] produces winners and losers like any other marketplace” (Marche, 2018, para. 43).

Studying GoFundMe’s rankings through a website biography

Algorithms play key roles in the management of attention and visibility online. They have “the task of modulating and curating the flow of contents, ideas and sociability” (Rieder et al., p.51). Think of Google’s PageRank algorithm, which
performs complex calculations involving data points such as in-links, a person’s search history, and geolocation to determine the order in which search results are listed. Algorithms of this type work as “epistemological machines” that crawl, index, cache, and ultimately order contents (Rogers, 2013, p.31). They also imbue a sense of authority and trustworthiness. It is not a small deed to be on Google’s first page of results for a given query. Algorithms, as communication expert Tarleton Gillespie has phrased it, “not only help us find information, they provide a means to know what there is to know and how to know it” (2014, p.167). In his words, they can be seen as having “powerful consequences for the social activities that happen with them, and in the worlds imagined by them” (Gillespie, 2003, p. 108).

Visitors to GoFundMe’s website also find campaigns arranged into lists and ranked by algorithms. As medium, crowdfunding websites not only host content; through their algorithms, they also create hierarchies pertaining to visibility and relevance. In this second part of my analysis, I focus on GoFundMe’s ranking practices and study them using the digital methods technique of constructing a website biography. I see this study of ranking on GoFundMe as continuing and adding to the critiques of survivorship and deservingness, which I presented in the previous section.

The approach I have chosen (website biography) is one way for studying ranking algorithms in GoFundMe and theorizing them. The technique focuses on the study of a website not in terms of its users or the content it hosts but as a medium with (ranking) methods. It is an example of what Roger’s calls “medium research” (2019, p.21). An ethnographic or journalistic study focused on GoFundMe’s users, by contrast, would inquiry, for example, how public data (e.g., number of ‘shares’ and donors) and rankings inform a person’s experience of medical campaigning. For instance, one cannot help but wonder how patients who practice crowdfunding interpret and live with the knowledge of these numbers. How is a person affected by learning that their campaign amassed a couple of shares and dollars instead of the hundreds of thousands collected by other patients?

This was one of the questions that Rachel Monroe, a journalist for The Atlantic, addresses in her article, ‘When Crowdfunding Gets Ugly’ (2019). Monroe interviewed an American couple, Lilia and Richard Roy, who ‘failed’ at medical crowdfunding. The couple’s goal was to raise $72,000, the amount “that they would need to sustain themselves for a year or two after the transplant” that Lilia needed (Monroe, 2019, para. 26). To Richard, the amount sounded too high. Nonetheless he was confident because “GoFundMe’s homepage was full of campaigns raising six-figure sums” (Monroe, 2019, para. 26). Richard is likely referring to GoFundMe’s list of top fundraisers.
The couple’s hope was, however, promptly crushed. “For days after the campaign went live, not a single person contributed” (Monroe, 2019, para. 27). They also expressed that “there’s a lot of secrecy and shame around the ones that don’t receive funding. If it’s a way to perform need, how must it feel to put yourself out there and not receive anything in return?” (Monroe, 2019, para. 27). Similarly, in her academic study of funeral campaigns on GoFundMe, Tamara Kneese (2018) conducted interviews as well as content analysis. She concluded that “the varied successes and failures of crowdfunding funeral campaigns could demonstrate how the lives of some individuals and groups are deemed more valuable than others” (Kneese, 2018, p. 2).

A critique of ranking practices could, alternatively, be design-oriented. If there are inequalities or unfairness in how campaigns reach their donors, could a crowdfunding platform be designed differently? Could there be, for example, a ranking that privileges medical campaigns which have not received enough funding? How could the business of crowdfunding be conducted (and coded) differently?

Reflecting on these questions, a group of academics from Simon Fraser University proposed that crowdfunding platforms should invest resources to develop crowdfunding skills among campaigners, create systems that “highlight disadvantaged groups on platform webpages and use donation pooling to distribute donations more equitably” (Snyder et al., 2019, para. 8). These scholars also offered as an example of such alternative crowdfunding models the organization Watsi. Unlike GoFundMe, Watsi is a non-profit platform for global health crowdfunding that operates only in low-income countries. According to media scholar Kenworthy, Watsi has (allegedly) “taken a relatively clichéd model for global charity […] and remade it as something new, evocative of the path-breaking technical power of Silicon Valley” (2018, para. 4).

As I mentioned earlier, I follow a different research strategy: a single-site history or website biography of GoFundMe. This approach involves taking one website as the unit of analysis. The website is, according to web historiographer Niels Brügger, one of five web ‘strata’ that can be studied longitudinally. The others include web elements (e.g., tabs on a webpage), a webpage, a web sphere, “which is the web activity related to a theme or an event,” and the web “as a whole” (Brügger, 2012, p. 754). When creating a ‘website biography’ one uses archived versions of a website and identifies changes implemented to its interface, branding, aesthetics, or in the case of my investigation, its ranking practices on GoFundMe and, then, uses these changes to narrate a history of the institution.

An example of this form of medium history is Brügger’s (2015) history of Facebook from 2004 to 2013. The work is not the history of Facebook. Rather, it is “an outline of a history of one single element of Facebook, namely the textual and
interactive media environment that users can see and interact with on the Web site and on mobile media” (Brügger, 2015, para. 3) Accordingly, Brügger proposed three periods. From 2008 to 2013 is the ‘where are you?’ period. During that time Facebook focused on profiles and self-representation gadgets. From 2006 to 2008 is what Brügger called the ‘what are you doing, and when?’ period. Facebook developed, during this period, new ways for sharing content and its mobile and geolocation applications. The last period is ‘where are you?’. From 2008 to 2013 Facebook focused on expanding its services across platforms, for example, by allowing users to sign-up into other services using their Facebook account.

My approach to GoFundMe is similar. I outline a history of a single element on the website: its rankings. Here, it is also worth noting that the results of my investigation on ranking algorithms are not based on studying code and datasets — those elements which would contain the rules that govern the performance of an algorithm’s tasks and calculations. Rather, I studied GoFundMe’s ranking algorithms like Brügger, that is, using information about them made available by GoFundMe and their presentation on the website.

To visit previous versions of GoFundMe’s website, one types the URL www.gofundme.com into the Wayback Machine’s search engine. The Wayback Machine is an interface built on top of the digital archive of the World Wide Web, founded by the Internet Archive, a nonprofit organization based in San Francisco (“About the Internet Archive”, n.d.). As can be seen in Figure 16, the results of the URL query are here presented as a timeline of the years in which the website was crawled and archived. Circles appear over calendar days to indicate that the website was archived on that particular day and time. The bigger the size of a circle, the larger the number of crawls. GoFundMe’s homepage has been captured 22,229 times between 12 March 2010 and 9 August 2019. By clicking on any of the calendar days on the timeline, one accesses and navigates the GoFundMe website as it was on that particular day. The results of the Wayback Machine are then repurposed for the research, as a way of playing back “the history of a webpage, most notably a website’s homepage” (Rogers, 2019, p.87).
My Wayback Machine analysis revealed that GoFundMe’s ranking practices have obeyed at least three different logics. First, campaigns were ranked according to freshness and emphasized the funders (2010-2013). Later, crowdfunding campaigns were recommended to users based on different metrics of ‘sociality’ (2013-2017). Afterward, all metrics of sociality were replaced by the criteria of ‘trending campaigns’, which privilege popularity and momentum (2017-2019). In the next section, I illustrate these results with selected screenshots and comment on them.

Ranking campaigns according to freshness, sociality, and trending

In 2010, GoFundMe’s homepage featured two separate lists of campaigns. The first list, as seen in Figure 17, appeared on the left side of the homepage. It featured crowdfunding campaigns dedicated to different causes and in different stages of completion. For example, the second place on this list was occupied by a medical campaign that supported a patient’s fight against colon cancer. It is not clear how this list was constructed or how the campaigns were ranked. The second list was located on the right side of the homepage, also seen in Figure 17. It was formatted as a ‘live feed’ of donations. Visitors to the GoFundMe website, at that moment in time, could see the amount of money that was being donated, how many hours ago a donation was made and by whom, and a link to the recipient’s campaign. This link functioned as an invitation for visitors to also donate. A year later, in 2011, the donation time was no longer measured in hours but in minutes.
By 2012, the list on the left side of the screen had disappeared and the ‘live feed’ was replaced by a grid of ‘recent donations.’ The screenshot in Figure 18 is an example of this grid. At the time the crawl was made, the most recent donation was to a campaign titled ‘A baby for Jullianne and Cory.’ It had received a donation of 100 dollars, exactly nine minutes ago.

Figure 18: Recent donations. Screenshot from www.gofundme.com. In 2012 GoFundMe’s homepage displayed campaigns in a grid organized according to recent donations. The grid privileged the visibility of the campaign with the most recent donation. I have obscured images that depict graphic accidents or children. Source: The Wayback Machine. 6 October 2012.
In 2013, GoFundMe’s homepage experienced a first significant deviation from its focus on ‘freshness,’ as expressed both by the criteria of ‘live’ and ‘recent’ donations. Visitors in 2013 could choose between seeing campaigns ranked according to ‘most popular,’ ‘near me,’ ‘live feed,’ and ‘funded by (Facebook) friends’ (see Figure 19). For each campaign, visitors could also see the amount of money donated and the cumulative number of people who donated to it. Then, by 2015, GoFundMe had introduced an additional feature. Instead of a list of campaigns ranked according to ‘most popular,’ the homepage displayed a list of campaigns that were ‘popular now.’ Also, the ‘live feed’ was replaced by a list of campaigns that were ‘almost there’ and, therefore, close to reaching their funding targets. Later, throughout 2017, visitors to the website found a selection of campaigns organized under the criteria ‘recommended for you’. In sum, GoFundMe’s logics had shifted from privileging freshness to privileging sociality. The term ‘sociality,’ as I used it here, describes the understanding of social activity as mediated, organized and valued by dominant social media platforms and their algorithms. That is, “what is claimed to be “social” is in fact the result of human input shaped by computed output and vice versa” (van Dijck, pp. 13-14).

GoFundMe’s shift from freshness to sociality vis a vis medical crowdfunding invites reflection. What is a ‘live feed’ made of donations to crowdfunding campaigns communicating? What is a visitor to the GoFundMe website meant to know through these rankings? One answer is that the ‘live feed’ aggregates an online public (or crowd) engaged in acts of generosity. That is, the live feed makes the work of the ‘crowd’ visible to visitor on the website. The constant flow of donations...
also serves as proof of the existence and availability of a crowd to which potential users, including patients in need, can make a plea. The ‘live feed,’ ultimately, communicates the effectiveness of GoFundMe as a service provider and gives visibility to those who donate.

GoFundMe is not unique in foregrounding a ‘live feed.’ The ‘live feed’ has become an established way for media audiences to know about suffering which is happening elsewhere. It is, for example, integral to reports of tragedies such as natural disasters and terrorist attacks by news organizations and citizen journalists. The live feed (for example on Twitter) is also ‘followed’ by online audiences via digital devices such as hashtags. This content reflects (or rather articulates) the event as it is happening online and on the ground. This particular way of knowing has been described by media witnessing and technology scholars as articulating an “eternal present of the eyewitness” (Chouliaraki, 2010, p.8), in which “online real-time witnessing pushes users to demand agency” (Martini, 2018, p.45). The event is articulated as continuously happening, and this presence (allegedly) demands our attention.

When it comes to the ‘feeds’ created by GoFundMe, respectively made of live and recent donations, one can ask: what event is the ranking algorithm articulating? What is it that one, as a visitor to GoFundMe’s homepage, is invited to witness through these recorded acts of solidarity? Maybe the answer is that visitors are bearing witness to a health crisis happening on the ground and to the public’s response to it. Thus, in the eternal present of the feed, the struggles which are recent and ‘fresh,’ may come to signify also those which are more urgent or deserving. In this sense, the live feeds are relentless and have the capacity to overwhelm audiences. The eternal present of the event almost certainly leads to compassion fatigue.

The logic of sociality retains elements of ‘freshness’ and the feed. The suffering and needs of others, as found in the campaigns, are still articulated and presented on GoFundMe homepage as feeds. However, sociality — ‘most popular,’ ‘near me,’ and ‘funded by (Facebook) friends’— prioritized the perspective and interests of the person visiting the GoFundMe website. If one carries the metaphor I introduces earlier further: a view of the event taking place online and, on the ground (a health crisis) is now personalized.

This second way of knowing (personalization) stands for a process where the content a person sees is filtered and ranked using their previous web activity and social media connections. This is, for example, how Amazon.com recommends books to its users and how the Facebook timeline displays content. It also how, until 2018, GoFundMe ranked campaigns. Personalization dictates that a person will most likely be interested in the same content that the people in their network, including, in this case, stories about human suffering. These newer forms of
witnessing have been theorized in the context of violence and natural disaster and in relation to ideas of personalized politics and engagement with social causes based on “personalized expressive forms and individual communicative networks” (Mortensen, 2015, p.1399). This phenomenon is described by Chouliaraki (2010) as “post-television” witnessing, in which, paradoxically, the protagonist of the account of suffering is not the victim but rather the benefactor.

Rankings and personalization, one can argue, create pockets (or filter bubbles) of care articulated by algorithms. The results are spaces of care defined and delimited by a person’s social network, location, and previous interactions. In this respect, the categories of ‘near me’ and ‘funded by friends’ offer an interesting contrast. The first emphasizes a sense of ‘localness’ and ‘community’. It is an invitation to care about those in one’s physical vicinity. The latter, ‘funded by friends,’ privileges the social network.

If one continues with the idea that through the data and interaction one comes to see or witness an ongoing health crisis, this same crisis acquires different outlines depending on the person visiting the GoFundMe’s website and the feed the focus on. In this space of personalized care, social media users will be more likely to encounter depictions of suffering which already people in their social networks favor, and which are thematically related. A second proposition appears to underline GoFundMe’s ranking choices: The illness story does not just need to be deserving, as I suggested in the previous section. It also needs to be relevant (Pariser, 2011) to the personal interests of the potential donors.

Since 2018, GoFundMe no longer ranks campaigns based on sociality. Trending is GoFundMe’s current dominant way of knowing about the illnesses of others. Trending is “anchored in the popularity principle” (van Dijck, p.133) and brings together elements from both freshness and sociality. As seen in Figure 20, for each one of these medical campaigns, visitors can see the title, the name of the person who runs it, a photograph, a few lines of the text, the amounts of money collected, and how many minutes ago the last donation was made.

In the organization’s own words, a ‘trending’ GoFundMe campaign “means that you’ve gotten a lot of support in a short amount of time, and it’s our goal to help campaign organizers understand how to reach this milestone” (“What does it mean”, 2019, para. 1). This becomes possible after the campaign has been opened more than 6 weeks ago, shared more than 25 times, and received at least four donations (“What does it mean”, 2019, para. 2). A campaign trends only for a certain amount of time. GoFundMe prepares users for these fluctuations and for the loss of momentum: “Don't worry if your campaign isn't trending or if it stops trending, it's all part of how viral fundraising works” (“What does it mean”, 2019, para. 4).
Trending in medical fundraising

Figure 20: Trending in medical crowdfunding in 2018. Visitors to www.gofundme.com are presented with a grid made of medical crowdfunding campaigns which are trending. For each of these campaigns, visitors see the title, the name of the person who runs it, a photograph, a few lines of text, the amount of money collected, and how long ago the last donation was made, counted in minutes.

*I have obscured images that depict graphic accidents or children.* Source: www.gofundme.com [9 June 2018].

That a campaign is ‘trending’ is a reflection of activity that happens across different platforms and that GoFundMe combines. And yet popularity is not simply out there, ready to be measured. According to José van Dijck it is, rather, “engineered through algorithms that prompt users to rank things, ideas, or people in relation to other things, ideas, or people” (2013, p.62). The trending and popular tend to be equated with the relevant. For example, “people who have many friends or followers are touted as influential, and their social authority or reputation increases as they receive more clicks. Ideas that are ‘liked’ by many people have the potential of becoming trends” (van Dijck, 2013, p.13). Here it matters that the popular is homogeneous — that is, certain types of campaign are more likely to become popular. As digitalization expert Rob Gleasure told The Outline: “As many happy stories as there are in charitable crowdfunding, there are a lot of really worthy causes when you browse these platforms that nobody has given a cent to” (Del Valle, 2017, para.6). A partial reason for their failure: “People haven’t come across them” (Del Valle, 2017, para. 6).

As the GoFundMe case demonstrates, harnessing attention is not easy. To go viral is the ultimate aspiration and it requires not just luck, but rather engineering and coordination. The patient must ask themselves: do I have highly connected nodes in a social network? How may I place my story in view of someone with influence? Thus, to the tyranny of optimism, medical crowdfunding adds the demand for being relevant, engaging, and well-connected. Those who do well in the moral economy of crowdfunding are social-media savvy.
Ranked bodies, deservingness, and calculated spaces of care

Crowdfunding is used for everything from financing indie video games to political projects. When the object of a crowdfunding campaign is a product, donors evaluate if the said product is interesting to them, if the creators look capable and if the deadlines are feasible. The crowdfunding campaigns that this chapter has explored are to pay for medical bills and cover a patient’s immediate needs. In medical crowdfunding, the consideration involves the lives and health of others.

I have described and critiqued aspects that I consider relevant to medical crowdfunding. I looked into public documents published by GoFundMe, including guidelines, templates, and blogs. I was interested in how GoFundMe frames storytelling as a fundamental aspect of crowdfunding. As it turns out, to animate the crowd and receive funds, patients need to tell ‘good stories.’ These stories are driven by what Frank (2013) calls “restitution plots” and embrace survivorship. They are about patients fighting for their lives, while remaining optimistic, determined, industrious, responsible, and in possession of a good character. Good stories are, ultimately, those which receive engagement and funds.

That these types of stories perform better than others invite further reflection regarding crowdfunding vis a vis existing issues of deservingness in healthcare. Instead of overcoming these issues, crowdfunding sites appear to recreate them. In fact, medical crowdfunding sites are illness storytelling machines for the era of “communicative bio-capitalism”– a term that Olivia Banner uses to describe media environments in which personal communication related to health are commodified. Through these sites, patients who can neither earn nor pay are offered the means to be productive as illness storytellers. That is to say, the patient may gain access to funds by marketing her illness stories to online donors. The illness story thus becomes transactional and those who lack online storytelling skills are at a disadvantage. Moreover, medical crowdfunding requires that sick people curate and tailor their stories to appeal to donors, potentially leaving out important aspects about their lives, feeling of anger, and issues of injustice. In this sense, medical crowdfunding offers a different view on the voice-enabling and therapeutic aspects of illness storytelling, present in the work of Frank, Jurecic, and Hawkins. In medical crowdfunding, the voice of the patient is limited by the depth of their need and the taste of the audience.

Given the nature of medical crowdfunding, I agree with experts who see web platforms like GoFundMe as “testimony environments [that] carry with them ‘pre-constructed’ relationships that can shape the nature and processes of testimony” (Adkins & Hancox, 2014, p.15). I investigated how these environments are also shaped by algorithms that rank personal stories of patients who suffer and are in need. With help of the Wayback Machine, I studied these different ranking practices and their outputs. The first type of ranking was a ‘feed’ made of recent
and live donations. I argued that these live feeds articulated the generosity of the crowd through the aggregation of individual acts of solidarity/care. I also claimed that from a different perspective, the same feeds articulated an ongoing healthcare crisis. The rankings created a space in which needs and generosity were displayed as taking place in a continuous and urgent present. They communicated: ‘this is happening now’ and the freshest thing is what matters the most.

The second type of ranking followed the logic of sociality. It prioritized and filtered campaigns using a person’s social-media activity and network ties. The outputs were different lists of campaigns, each arranged based on criteria such as ‘popular now’ and ‘funded by Facebook friends.’ Thus, visitors to GoFundMe came to know about the stories of patients through a personalized space of care. This personalized ranking may also narrow a person’s views.

Lastly, I reflected on GoFundMe’s current dominant ranking: trending campaigns. The term describes online entities that sustain significant attention for a limited period of time. It is a measure of popularity and thus competitive and work-intensive. As a way of knowing, I argued, ‘trending’ privileges what is already popular, often equating popularity with relevance and deservingness.

By attending GoFundMe’s different ranking practices, I expanded existing critiques regarding issues of deservingness in healthcare and in medical crowdfunding. When it comes to medical crowdfunding, ideas of deservingness become entangled with the quantification practices that underline crowdfunding sites and, more generally, the social web and its attention economies. Medical crowdfunding has, indeed, winners and losers. However, in our current media environment, which favors popularity, we hear mostly about the first category. Those in the second category have failed to gather attention and funds and usually do not feature in GoFundMe’s rankings or written about in the media as ‘inspirational stories.’ Instead, these campaigns are hidden away on the website (which visitors are unlikely to browse in detail) and travel slowly through social-media sites. These medical crowdfunding campaigns often generate only a handful of donations.

While conducting research, I visited a number of these underperforming medical crowdfunding campaigns. One of them was run by an older man diagnosed with cancer. He was confused, as he expressed in one of the campaign updates. He had opened the campaign, but nobody was donating. He asked: why? The answer to his question, at least based on corporate discourse and ranking criteria, is that he has not posted enough on Facebook and that he needs to write a better story and be better connected online. These are the stories of ranked bodies.
Chapter 5 Conclusions: Algorithmic visibility, edited selves, and liveness.
Illness is the subjective experience of the person who is sick. Diseases are disorders in the functioning of a person's body. Doctors read and measure diseases with scientific equipment. Illnesses are told in the first-person. These personal accounts of illness are called ‘illness stories’ (Hawkins, 1999; Frank, 2013). They address suffering and hope and the radical alterations that illness introduces in a person's life. Telling stories about illness —be that through diary-keeping, public speaking, writing memoirs, or posting online— involves the ordering of experience, reflection, and the (potential) reclamation of agency.

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

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

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

I emphasized in this review also the contributions of sociologist Arthur Frank (2013) and literary experts Anne Hunsaker Hawkins (1999) and Anne Jurecic (2012). These authors identify types of illness narratives and master plots, which are recurring stories with a great deal of rhetorical power. Through these narrative types, Frank, Hawkins, and Jurecic exemplify how illness stories are unique to the people who tell them but, at the same time, are crafted using shared cultural resources, which can be studied. This last point about the shared characteristics of stories became relevant in my own argument, as I, too, proposed
types. Moreover, I referenced and built throughout my investigation on Frank’s story types, specifically, on the restitution narrative (which are stories about cure) and the quest narrative. The quest is about patients searching for meaning beyond treatment and becoming ‘wounded storytellers’ and healers, that is, people who share their personal stories to help others in similar circumstances.

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

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

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

The intersection of illness and electronic literature is interesting and, also, understudied. Especially intriguing is the deployment of technical and narrative devices such as hypertext, non-linear storytelling, and generative design in the communication of illness. As an example, I discussed ‘Queerskins’ (Szilak, 2012), a hypertext novel about a young gay doctor who dies during the AIDs epidemic.
The novel is read by navigating and exploring the dairy entries and photographs left behind by the main character, which are displayed on the screen in a collage-like manner. The fragmented nature of the reading conveys a sense of loss and trauma. In ‘Reagan’s Library’ (Moulthrop, 1999), another hypertext work, the text on the screen is programmed to change as the reader progresses. This degenerative writing embodies a metaphor for Alzheimer’s disease. Similarly, players of the video games ‘Depression Quest’ (Quin, 2016) and ‘That Dragon, Cancer’ (Green, 2016) are confronted with decision-making and puzzles that evoke the fatigue of depression and the labyrinthic life of caretakers.

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

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

Moreover, I framed online illness storytelling by patients as the work of “networked selves” (Papacharissi, 2018; 2019) and micro-celebrities (Senft, 2008). Networked selves are people who use technology to tell stories about their selves (and their illnesses) and negotiate their place in the world. Micro-celebrity is an expression of the networked self. It involves curating personal information to draw attention and managing audiences. In this section, I reviewed the work of authors like Orgad (2005), McCosker (2013), and Stage (2017), who brought illness theory together with ideas of online self-representation, affordances, and networked selves. For example, Stage studied blogging and proposed the concept of the entrepreneurial pathography, on which I built on Chapter 2. Entrepreneurial pathographies are the illness stories of cancer bloggers who raise awareness and funds for charities, and who thus use their stories to generate value.
Overall, I learned from authors like Papacharissi, Stage, McCosker, and Orgad that media affordances and the methods embedded in platforms, that is, how platforms organize activity and create data, shape illness storytelling in significant ways. The study of social media illness stories required sensitivity to affordances, platforms, and online vernacular practices and to how these elements come alive in people’s hands.

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

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

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

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

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

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

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

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

Sophia alternated between talking about illness and her love for fashion. Daniel raised awareness about having a rare form of cancer and envisioned popularity as a vehicle to gather information about this condition. When it came to his medical exams, he invited viewers to come ‘along for the ride’ and charmed them with raw honesty and humor. By choosing which aspects of their illnesses to show, and by alternating between speaking about life as patients and their other interests, they managed to, as I came to interpret it, create an opportunity to be
more than their diseases. After Sophia and Daniel announced that they were
dying, as expected, their health and energy and vlogging started to change and
decrease. In Sophia’s case, there were prolonged periods of silence. These changes
led to some viewers questioning the value and sincerity of the vlogging activity.
Is vlogging a productive activity for terminal patients? Do the viewers get to see
the ‘whole story’?

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

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

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

Instagram posts typically include images, captions, and hashtags. An image could
be of a sonogram, posted to Instagram, on the anniversary of a stillbirth. The
caption would recall the event and the resulting grief and include hashtags such
as ‘stillbirth,’ ‘still loved,’ ‘angel mom,’ and ‘angel baby.’ Clicking on any of these
hashtags, redirects users to related content about stillbirth and to a community of
bereaved parents. From the outset, I was intrigued by these hashtags practices and set to repurpose them in my analysis. I saw them a specialized language and data about motherhood and grief. What was tagging affording bereaved women?

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

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

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

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

The hierarchies of visibility that govern medical crowdfunding have been amply addressed by academic literature and journalistic media (Scott, 2014; Snyder et al., 2017; Berliner & Kenworthy, 2017; Paulus & Roberts, 2017; Petersen, 2017). This literature reveals that, in medical crowdfunding, the stories that perform best are stories about ‘good people’ and survivor-like patients who have fallen ill.
and for whom health is possible, the only matter being funding. Indeed, sick people who are financially unstable need to perform their deservingness on GoFundMe as a way to access healthcare. I added to these critiques by underscoring how telling personal stories on GoFundMe is an activity also encouraged and governed by GoFundMe’s corporate discourse and its changing ranking infrastructures. This involved using the Wayback Machine to trace meaningful changes in GoFundMe’s interface and ranking practices.

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

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

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

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

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

Ultimately, this book has considered how social media supports but can also limit a sick person's capacity to recover their voice as the teller of their own story. Together, the three case studies illustrate how concepts that experts use to theorize illness storytelling —such as voice, agency, ‘searchable talk’, and wounded healing— are informed and complicated by social media’s treatment of visibility. They demonstrate that in the study of social media, illness stories and illness theory cannot be divorced from issues of ranking, popularity, tagging, and audience management. Their interconnection with these issues has significant consequences. Social media has made storytelling available but listening and attention selective and competitive. We will most likely only know the illness of those who are already liked and are media-savvy. Thus, it is necessary that the study of illness stories, as I have aimed to do in my work, develops means to reflect on these implications.
The popularity-driven and work-intensive environments of social media also raise additional questions that follow from my case studies. Do the stories of popular patients create expectations for those who also fall ill? Are they a new Ars Moriendi – that is, an instruction for how to die well? Do teenagers with cancer aspire to be like Sophia, perhaps without understanding the work and risk involved? Is this striving something that doctors need to discuss with their young patients, in the same way that school teachers advise on media literacy? Algorithmic visibility also affects those who tell stories. There are networks of helpful users and community. However, there is also the risk of exposure and judgment or of having a platform to speak but not being listened to. If we follow the logic of the medium uncritically, we create inequalities that are algorithmically supported. As illness story researchers, we need to look carefully at social media machines and their conditions of possibility.

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

Contributing to a digital agenda in the health humanities

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

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

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

This dissertation intends to contribute to the cultural study of illness and to debates about the use of social media as a vehicle for illness storytelling. More concretely, it examines how people use social media to speak about their illnesses, the types of stories they tell, and what telling these stories affords them. The results are three types of social media illness stories; namely, the stories of popular bodies on YouTube, tagged bodies on Instagram, and ranked bodies on GoFundMe, a crowdfunding site.

A disciplinary contribution is made by positioning social media illness stories and the types of stories I proposed, more specifically, within existing research in the humanities. I have reviewed how authors from the fields of literature, narrative studies, cultural studies, history, mass media, electronic literature, and social media studies approach the subject of illness and issues of narrating, voice, and agency. The outcome is a disciplinary context for understanding the study of illness stories on social media both in relation to concepts of narrative, voice, and agency as well as medium-specificity, platforms, affordances, and self-presentation strategies such as micro-celebrity, as developed by authors such as Zizi Papacharissi, Carsten Stage, Jill Walker Rettberg, and Ruth Page.

A theoretical contribution is made through the types of social media illness stories that I proposed; namely, of popular bodies, tagged bodies, and ranked bodies. Each type of story addresses socio-technical conditions of social media which are essential to how illness is told online. I theorize these social media illness stories as stories with specific structures and goals pertaining to recovering agency, particularly through ideas of wounded-healing, a concept proposed by sociologist Arthur Frank, and testimonial pathographies, a notion found in the work of Anne Hunsaker Hawkins. Then, I built upon such concepts by applying them to social media stories through the lens of micro-celebrity, ‘hashtag publics,’ and ranking cultures (digital objects handled by the methods embedded in platforms).

A methodological contribution is made by proposing digital methods techniques, which are research techniques native to social media, to study the stories of popular, tagged, and ranked bodies. Digital methods, as developed in the work of Richard Rogers, are techniques developed by repurposing the digital elements and methods already present in platforms. Through the use of digital methods I illustrated productive ways for conducting medium-specific, data-driven social media research on the subject of illness. And, more precisely, I performed a ‘filtered reading’ to the study of vlogs on YouTube,
undertook co-hashtag network analysis on Instagram, and studied the ‘website biography’ of www.gofundme.com using the Wayback Machine of the Internet Archive.

Chapter 2 engages with the stories of popular bodies. These are the stories of patients who vlog on YouTube and practice micro-celebrity. Popularity is both a status (to be well-known and liked) and a product of accumulating views and comments, which, in turn, lead to vloggers ranking high on YouTube's search engine. The chapter analysis the vlogs these two cancer patients, Sophia Gall and Daniel Toms, who accumulated millions of views on YouTube before passing away. I offered insights on how illness is narrated using lifestyle vlogging, a format vernacular to online media, and how becoming popular online, as was the case of Sophia Gall and Daniel Toms, shapes both storytelling and illness experiences. The vlogs were studies through a ‘filtered reading,’ that means that the vlogs were analyzed, first, chronologically, which corresponds to ‘seeing’ the vlogs filtered ‘from older to newer’. Second, the vlogs were analyzed based on engagement, that is, as reorganized from ‘most engaged to least’. Vlogging and popularity afforded the vloggers a sense of agency over their life stories and became a lifeline to the world. Through vlogging Sophia and Daniel also challenged expectations about sick people’s passivity; in fact, Sophia and Daniel were entrepreneurial patients. At the same time, the public nature of their communication made them the subject of the scrutiny. As their health worsened, Sophia and Daniel became unable to vlog steadily. Some viewers grew concerned about the vloggers and others questioned, publicly, the value and sincerity of their online activities. Responding to these accusations and managing this concerned audience became, too, part of vlogging at the end of life, demanding the reevaluation of ideas of agency vis a vis the demands of popularity.

Chapter 3 engages with the stories of tagged bodies. These are stories about people who suffer from disenfranchised conditions and use Instagram to share (and tag) their personal experiences. The goals of this public storytelling are to fight stigmas and create communities. By adding tags, otherwise ‘invisible’ personal experiences can be found by other Instagram users and placed into networks. In other words, on Instagram, breaking the silence involves patients making themselves searchable and networked. To develop these ideas, the chapter uses co-hashtag network analysis to examine the communication and tagging practices of women who have suffered stillbirth. The analysis reveals three hashtags practices. The first is the use of hashtag campaigns to coordinate expressions of grief and make them ambient. The second is to use posts and hashtags to share personal histories of pregnancy loss using tropes of journeys and sisterhood. The third practice pertains to how brands use hashtags related to pregnancy loss to target bereaved women and sell them products. This storytelling and tagging activities (and their relevance) were theorized as media-specific manifestations of wounded healing, a concept relevant in the field of illness narrative. Wounded healing refers, in this context, to how women who have suffered stillbirth regain agency as educators and issue makers through online storytelling and tagging.

Chapter 4 engages with the stories of ranked bodies. These are stories of sick people in financial distress who use crowdfunding sites such as GoFundMe to raise funds to pay for their medical treatment. The chapter presents an analysis and subsequent critique of medical crowdfunding’s on-sided advise to market personal illness stories as cure-oriented, or as restitution stories in the language of survivors. This one-sidedness may
come to exclude conditions which cannot be narrated in relation to a cure such as terminal illness or chronic conditions. Also, too much emphasis on personal responsibility downplays the systemic issues and inequalities which lead people to crowdfund. In doing this GoFundMe recreates long standing economies of deservingness. In addition, the chapter explores how campaigns and the illness stories told in them will not only be evaluated by potential donors, who decide who they want to fund. They are also ranked (that is, given a status amongst other stories) by GoFundMe’s algorithms. To study this ranking culture the chapter presents an historical investigation – a website biography—about the different ranking criteria GoFundMe has used in its website in the last ten years. The current emphasis on trending, equates popularity with deservingness, once again creating potential inequalities. In a regime of ‘trending,’ people with less marketable conditions and limited digital literacy are at risk of not receiving funds.

I conclude the dissertation by drawing together insights from the different case study chapters and using them to reflect on how platform-enabled visibility as well as the sociotechnical conditions of popularity, tagging, and being ranked both enhance but also diminish the political potential of illness storytelling. I also reflect on the digital debate in the health humanities: engagement with medium-specific research, as the one I have developed, can further the study of illness storytelling as it continues to develop online.
Samenvatting

Ziekte online.
De populariteit, tagging en ranking van lichamen op sociale media.

Dit proefschrift beoogt bij te dragen aan de culturele studie van ziekte en aan debatten over het gebruik van sociale media als middel voor storytelling over ziekten. Concreet wordt onderzocht hoe mensen sociale media gebruiken om over hun ziekte te praten, het soort verhalen dat ze vertellen en wat het vertellen van deze verhalen hen biedt. Drie prominente vormen van zulke ziekteverhalen op sociale media staan in deze studie centraal; de verhalen van populaire lichamen op YouTube, van getagde lichamen op Instagram en van gerankte lichamen op GoFundMe, een crowdfunding website.


Een theoretische bijdrage wordt geleverd via de voorgeneste typen ziekteverhalen op sociale media; die van populaire lichamen, getagde lichamen en geranke lichamen. Elk type verhaal wordt bestudeerd in de context van de socio-technische aspecten van de platformen die essentieel zijn voor de manier waarop verhalen over ziekte online worden verteld. Ik theoretiseer deze ziekteverhalen als verhalen die ten doel hebben keuzevrijheid en handelingsbekwaamheid te herstellen dan wel te vergroten, met name door strategieën die voortborduren op de noties van ‘wounded healing’, een concept van socioloog Arthur Frank, en ‘testimonial pathographies’, een begrip uit het werk van Anne Hunsaker Hawkins. Vervolgens heb ik voortgebouwd op deze concepten door ze toe te passen op sociale media verhalen die zich afspelen in de context van typische sociale media fenomenen: micro-beroemdheid, ‘hashtag publics’ en ‘ranking cultures’ (deze fenomenen zijn het resultaat van methoden die zijn ingebed in platformen en die resuleren in digitale objecten zoals de hashtag).

Een methodologische bijdrage wordt geleverd door de ontwikkeling en toepassing van digital methods. Digital methods, zoals ontwikkeld in het werk van Richard Rogers, gaat uit van het gebruikmaken van digitale elementen en methoden reeds aanwezig in de infrastructuur van een platform. Door het gebruik van digital methods heb ik productieve manieren ontwikkeld om verhalen over ziekte op sociale media te bestuderen met oog voor de mediumspeicifiek, datagedreven dynamieken van platformen. In de studie van vlogs op YouTube pas ik een ‘gefilterde lezing’ toe, deed een co-hashtag-netwerkanalyse
op Instagram en bestudeerde de ‘website-biografie’ van www.gofundme.com met behulp van de Wayback Machine van het Internet Archive.

In het tweede hoofdstuk behandel ik de verhalen van populaire lichamen. Dit zijn verhalen van patiënten die vloggen op YouTube en daar micro-beroemdheden zijn. Populariteit is zowel een status (bekend en geliefd zijn) als een product van opeenvolgende views en commentaren, die er op hun beurt toe leiden dat vloggers hoog scores in de zoekmachine van YouTube. In dit hoofdstuk analyseer ik de vlogs van twee kankerpatiënten, Sophia Gall en Daniel Toms, die miljoenen views op YouTube verzamelden voordat ze stierven. Deze analyse biedt inzicht in hoe ziekteverhalen worden verteld met behulp van lifestyle vlogging, een format dat in sociale media wordt gebruikt en waarmee Sophia Gall en Daniel Toms zeer populair werden. Dit format beïnvloedt zowel de inhoud van storytelling als de ervaringen van het ziek-zijn.

Door middel van een ‘gefilterde lezing’ zijn deze lifestyle verhalen bestudeerd. Dit betekende dat ik eerst de vlogs chronologisch heb geanalyseerd, beginnend bij de oudste vlog. In tweede instantie werden de vlogs geanalyseerd op basis van betrokkenheid, dat wil zeggen gereorganiseerd van ‘meest betrokken naar minst betrokken’. Vloggen en populariteit gaven de vloggers een gevoel van keuzevrijheid in de vormgeving van hun levensverhalen en fungeerden als een reddingsboei. Door te vloggen gingen Sophia en Daniel ook in tegen het beeld van passieve zieken; in feite waren Sophia en Daniel ondernemende patiënten. Tegelijkertijd werden ze door het openbare karakter van hun communicatie kritisch bekeken. Naarmate hun gezondheid verslechterde, konden Sophia en Daniel minder vaak vloggen. Sommige kijkers maakten zich zorgen over de vloggers en anderen vroegen publiekelijk naar de waarde en oprechtheid van hun online activiteiten. Reageren op deze beschuldigingen van inauthenticiteit en het onderhouden van dit bezorgde publiek werden onderdeel van het vloggen aan het einde van hun leven. Dit vraagt om reflectie op onze ideeën over handelingsbekwaamheid in relatie tot een cultuur die populariteit prioriteert.

Hoofdstuk 3 gaat in op de verhalen van getagde lichamen op Instagram. Deze zijn afkomstig van mensen die lijden onder erbarmelijke omstandigheden en Instagram gebruiken om hun persoonlijke ervaringen te delen en te taggen. Doelen van deze openbare verhalen zijn het bestrijden van stigma’s en de creatie van gemeenschappen. Door tags toe te voegen, kunnen persoonlijke ervaringen gevonden worden door andere Instagram-gebruikers en in netwerken worden geplaatst die anders ‘onzichtbaar’ zouden zijn. Met andere woorden, op Instagram houdt het doorbreken van de stilte in dat patiënten zichzelf vindbaar maken in het zoeksystem en zichzelf onderdeel maken van een netwerk. Om deze ideeën te ontwikkelen, gebruikt het hoofdstuk ‘co-hashtag network analysis’ om de communicatie- en tagging-praktijken (de manieren waarop hashtags strategisch worden gebruikt in posts) van vrouwen die een doodgeboorte hebben meegemaakt, te onderzoeken. De analyse onthult drie hashtag-praktijken. De eerste is het gebruik van hashtag-campagnes om uitingen van verdriet te coördineren en ze te introduceren als onderdeel van sociale media feeds. De tweede is om posts en hashtags te gebruiken om persoonlijke verhalen van doodgeboortes te delen met behulp van vaker voorkomende uitdrukkingen (tropes) rond ‘journeys’ en ‘sisterhood’. De derde praktijk heeft betrekking op hoe merken hashtags gebruiken, die verband houden met zwangerschapssluit, om nabestaanden te bereiken en producten te verkopen. Deze
storytelling en tagging-activiteiten (en hun relevantie) werden getheoretiseerd als mediaspecifieke manifestaties van ‘wounded healing’, een concept relevant in het gebied ziekteverhalen. ‘Wounded healing’ verwijst in deze context naar hoe vrouwen die een doodgeboorte hebben meegemaakt, hun handelingsvermogen kunnen herpakken door educatief-informerend op te treden en aandacht te vragen voor dit onderwerp via storytelling en tagging.

In het vierde hoofdstuk ga ik in op verhalen van gerankte lichamen. Dit zijn de verhalen van zieke mensen in financiële nood die crowdfunding websites als GoFundMe gebruiken om geld in te zamelen voor hun medische behandeling. Het hoofdstuk zet de analyse van deze verhalen uiteen en geeft kritiek op de eenzijdige nadruk van medische crowdfunding op verhalen die gaan over persoonlijk herstel. Daarnaast onderzocht ik hoe campagnes en de daarin vertelde ziekteverhalen niet slechts worden geëvalueerd door potentiële donoren die beslissen wie ze willen financieren. Ze worden ook gerangschikt (dat wil zeggen, tussen andere verhalen een bepaalde status verleend) door de algoritmen van GoFundMe. Om deze ‘ranking cultures’ te bestuderen, deed ik historisch onderzoek - in de vorm van een website-biografie - naar de verschillende rangschikkingscriteria die GoFundMe de afgelopen tien jaar op zijn website heeft gebruikt. Verhalen van genezing of overleving worden op het platform gepropageerd en zijn meer succesvol. Deze eenzijdigheid kan ertoe leiden dat aandoeningen die niet kunnen worden verteld in de context van genezing, zoals terminale ziektes of chronische aandoeningen, uitgesloten worden. Teveel nadruk op persoonlijke verantwoordelijkheid bagatelliseert ook de systemische problemen en ongelijkheden die mensen bewegen tot crowdfunding. Door deze eenzijdigheid versterkt GoFundMe een op merites gebaseerde economie. De huidige nadruk op trending stelt populariteit gelijk aan merites en creëert daarmee potentiële ongelijkheden. In een regime van trending lopen mensen met minder (goed) behandelbare of onbehandelbare aandoeningen en beperkte digitale geletterdheid het risico geen geld te ontvangen.

Ik sluit het proefschrift af door inzichten uit de verschillende hoofdstukken en uit de case studies samen te brengen en te gebruiken om na te denken over hoe zichtbaarheid op platformen en de sociotechnische voorwaarden van populariteit, tagging en ranking het politieke potentieel van ziekteverhalen kunnen versterken, maar ook kunnen verminderen. Met dit proefschrift wil ik daarnaast aantonen dat betrokkenheid van gezondheidswetenschappen bij mediumspeekse onderzoek, zoals ik dat heb ontwikkeld, de studie van online ziekteverhalen en storytelling kan bevorderen.
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