Illness online

Popular, tagged, and ranked bodies

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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 LGBT 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 today20, 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

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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).

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 Go Fund Me], 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.
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 Julianne 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).

Figure 19: Ranking campaigns according to sociality. Screenshot from www.gofundme.com. In 2013, GoFundMe’s homepage displayed campaigns ranked according to ‘most popular,’ ‘near me,’ ‘live feed,’ and ‘funded by (Facebook) friends.’ For each campaign, users could see the amount of money donated and the cumulative number of people who had donated to it. Source: The Wayback Machine. 20 April 2013.

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).
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 the 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.