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### Illness online

*Popular, tagged, and ranked bodies*

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### Publication date

2020

### Document Version

Other version

### License

Other

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### Citation for published version (APA):

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

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***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<sup>1</sup>. 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’<sup>2</sup> 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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<sup>1</sup> The numbers were recorded on 3 February 2020

<sup>2</sup> 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.<sup>3</sup> 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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<sup>3</sup> 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!!!’<sup>4</sup>, 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

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<sup>4</sup> 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,’<sup>5</sup> in which she summarizes past events including her diagnosis, ‘DAY IN THE LIFE OF A CANCER PATIENT’,<sup>6</sup> ‘Normal people vs. people with cancer’<sup>7</sup> and the joyful, ‘I’M CANCER FREE!’<sup>8</sup>, 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<sup>9</sup>” 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?’<sup>10</sup> and ‘Scans, Scans, Scans,’<sup>11</sup> respectively, number 46 and 51 on Figure 1. After the last round of radiation, Sophia (and her viewers) wait for the latest scans results.

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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<sup>5</sup> So Fia [Mar 14, 2016] My Cancer Story // SO FIA [YouTube video]  
<https://www.youtube.com/watch?v=1xl6c745fQI>

<sup>6</sup> So Fia [April 4 2016] ‘DAY IN THE LIFE OF A CANCER PATIENT // SO FIA’ [YouTube video]  
<https://www.youtube.com/watch?v=4QK8cl-n3uw>

<sup>7</sup> 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)

<sup>8</sup> So Fia [May 27 2016] ‘3 Words - I’M CANCER FREE! | SOPH FIA’ [YouTube video]  
<https://www.youtube.com/watch?v=RxNje8d2eWI>

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

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

<sup>11</sup> So Fia [May 24 2017] SCANS, SCANS AND SCANS!! Day in the Life Vlog [YouTube video]  
<https://www.youtube.com/watch?v=q0sOdKj-mnM>

community. During this time, video topics include the questions: ‘Doctors lie?’<sup>12</sup> and ‘what is cancer?’<sup>13</sup> (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’<sup>14</sup> (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.<sup>15</sup> 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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<sup>12</sup> PeeWeeToms [January 17 2018] ‘Do Doctors Lie? Do People Lie About Cancer?’ [YouTube video] <https://www.youtube.com/watch?v=TZW86Hxa0uU>

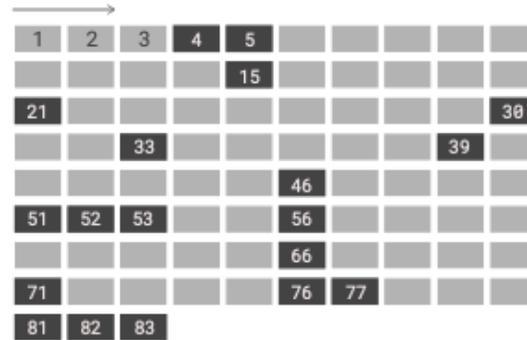
<sup>13</sup> PeeWeeToms [January 18 2018] ‘What Is Cancer? Cancer Explained Simply’ [YouTube video] <https://www.youtube.com/watch?v=Pd3PK5u4tdQ&t=149s>

<sup>14</sup> So Fia [May 28 2017] ‘My Cancer Is Worse Than Ever - Scan Results’ [YouTube video] <https://www.youtube.com/watch?v=69wLABEV1YI&t=331s>

<sup>15</sup> PeeWeeToms [April 24 2018] ‘CANCER HAS WON IT'S GAME OVER’ [YouTube video] <https://www.youtube.com/watch?v=9S9Q2T1B6xE&t=287s>

## Sofia Gal

videos uploaded to youtube in chronological order



# position of video in the timeline

### Cancer Free

4 Flying to America. 5 Proton therapy + shopping!!! 15 My cancer story. 21 'I'm cancer free'. 30 I'm in a magazine!!! + huge shopping haul!! 33 The price of a life | A short film.

### Relapse

39 The day I dreaded forever, my cancer relapse story. 46 Does chemotherapy hurt? Snapchat q&a. 51 Scans, scans and scans!! Day in the life vlog.

### Ceasing Treatment

52 My Cancer Is Worse Than Ever- Scan Results.'

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**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.



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.

<b>Type of comment</b>	<b>Sophia Gall</b>	<b>Daniel Toms</b>
<b><i>Support and sympathy</i></b>	<p>‘Omg I wish I could hug you it will be ok’</p> <p>‘Sophia, your avocado socks did brighten my day, but not as much as your beautiful smile’</p> <p>‘Go to Thailand!’</p>	<p>‘Enjoy your life to the fullest man. Seize the day. Fuck cancer’</p> <p>‘PeeWeeToms you deserve at least 1 million subscribers, man! Stay strong’</p>
<b><i>Shared stories</i></b>	<p>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</p> <p>Last year I lost my mother to cancer. I know how much It hurts</p>	<p>I am sorry that you have to go through this. My mother lost my older sister's dad to skin melanoma. It is hard</p>
<b><i>Medical advice</i></b>	<p>Sophia, there is a cure. Please look up the truth about Cancer both on YouTube and on the Internet</p> <p>Can’t you amputate the leg to get rid of the cancer?</p> <p>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?</p>	<p>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</p> <p>All these disrespectful people in the comments claiming they have a cure, like they're certified doctors with breakthrough remedies. Get over yourselves</p>
<b><i>Religion</i></b>	<p>I hurt for you. Do you know Jesus? Are you a Christian?</p>	<p>...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</p>
<b><i>Critique</i></b>	<p>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</p> <p>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</p>	<p>You should really stop vlogging and be with your family and friends</p> <p>Fake cry. U are one of those youtubers/streamers who fake injury to get donations. Pathetic</p> <p>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</p>

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

**Table 1: 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 were captured 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'.<sup>16</sup> 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'.<sup>17</sup> 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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<sup>16</sup> So Fia [August 25 2017] 'HEALTH UPDATE + Q & A!' [YouTube video]  
<https://www.youtube.com/watch?v=L3eYy4EpTJc&t=237s>

<sup>17</sup> So Fia [February 17 2018] Where I've Been? Cancer Update + My Shorty Award Nomination!! [YouTube video]  
[https://www.youtube.com/watch?v=1\\_OVksH4NY&t=846s](https://www.youtube.com/watch?v=1_OVksH4NY&t=846s)

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'<sup>18</sup> 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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<sup>18</sup> PeeWeeToms [February 7 2018] 'My Cancer Update 07-02-2018 - I Wish I Had Good News - My Cancer Journey' [YouTube video] <https://www.youtube.com/watch?v=QZep-HG1BXA>

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.<sup>19</sup>

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.

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<sup>19</sup> February 12 2020