



## Digital Oncology

### Vlogging at the end of life

Despite advances in treatment options, many patients diagnosed with cancer ultimately face the premature ending of their life. Under these circumstances, patients 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. Their storytelling constitutes a particular type of illness story, distinct from other related categories. For example, although restitution narratives are driven by recovery, end-of-life stories come forth in relation to unattainable health and the contemplation of death. Health-care professionals may support the storytelling process. Techniques include diary keeping, reading stories written by other patients, and the co-creation of stories between patients and spiritual guides. Beyond having a therapeutic function, these personal stories are valuable pedagogical materials that help health-care professionals understand the end-of-life experience and they create more efficient care for patients.

Outside of a direct medical context, people encounter end-of-life stories in non-fiction books, blogs run by patients, and most recently, social media. As a result, we sought to assess the two most popular YouTube video blogs (vlogs) run by patients with terminal cancer. To select the vlogs we did a search on YouTube on July 3, 2018, using the words “cancer vlog” and setting the filter to return channels organised according to view count, and selected the two channels with the highest number of views that were active in 2018. We took into account the vlogging activity from the start of the vlogs until Oct 12, 2018, shortly after the death of the second vlogger. The first vlogger is Sophia Gall, an Australian teenager, active on YouTube from December, 2015, to February, 2018. Her vlog has 83 videos, 156 180 followers, and more than 8 000 000 views. The second vlogger is Daniel Toms, a British man in his thirties. Active from September, 2016, to September, 2018, his vlog has 198 videos, 152 947 followers, and around 5 000 000 views. We qualitatively analysed how the end-of-life experience is communicated in these vlogs and how other YouTube users reacted to the content produced by these patients with a terminal illness.

Sophia and Daniel’s vlogs (figure) start as restitution stories, driven by the goal of achieving health. Sophia suffers from osteosarcoma, has finished chemotherapy, and will travel to the USA for proton therapy. During this time, her videos resemble lifestyle vlogs. Her attitude is positive, she shares details of her travels and talks about makeup and clothes. Then, after receiving numerous requests, Sophia begins to vlog more about her illness and, having completed treatment, uses her vlog to

reflect on life as a former patient. For example, she posts the videos “My cancer story”, in which she summarises past events including her diagnosis, “Day in the life of a cancer patient”, “Normal people vs. people with cancer”, and “I’m cancer free”. However, she also uploads poetry, speaks with a local magazine and wants to collaborate with makeup artists. Repeatedly, Sophia reminds viewers to hit the subscribe button. Weeks later, Sophia posts a troubling update—her cancer has returned. During this new phase, 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 “Does chemotherapy hurt?” and “Scans, Scans, Scans”. After the last round of radiotherapy, Sophia (and her viewers) wait for the latest scan results.

The second vlogger, Daniel (figure) was diagnosed with a pleomorphic sarcomatoid carcinoma. Frustrated by the lack of information about his condition, Daniel argues that becoming a well-known vlogger can help him gather new insights and educate people. He reassures viewers he will speak about cancer but intends to be funny and entertaining. During this phase, videos include “Doctors lie?” and “what is cancer?”. He also documents his treatment and answers viewers’ questions.

Indeed, neither Sophia nor Daniel started vlogging as patients with terminal cancer. Rather, they became this in front of their viewers. Sophia revealed that she was stopping treatment in the video “My Cancer Is Worse Than Ever - Scan Results”. She looks directly at the camera and pronounces that she “can’t explain [...] how painful this is” and plans to enjoy her life by travelling the world with her family. She asks for viewer participation “If you guys have any good ideas of what to do in those places, let me know in the comments”. She also thanks them for their support; vlogging has enabled her to “get away from everything” and raise awareness. Similarly, Daniel published the video “Cancer has won”, in which he says “They just told me it is inoperable now [...] I’m now documenting the end of my life”. These videos are, in fact, the most popular in both vlogs. Sophia’s received 2.2 million views and Daniel’s 2.4 million views.

After the vloggers’ announcements of incurable disease, viewers offered support, shared their own stories, and gave advice. At the same time, distrust in medicine was common, with viewers commenting that a cancer cure exists but is kept secret. Others questioned Sophia and Daniel’s medical choices and described vlogging as a poor use of their limited time. So-called trolls left hateful messages wishing for the vloggers’ deaths.

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For more on **meaning construction in palliative care** see *Am J Hosp Palliat Care* 2006; **23**: 309–16

For more on **restitution narratives** see Frank AW. The wounded storyteller: body, illness, and ethics. Chicago; London: The University Of Chicago Press, 2013; *Psychooncology* 2016; **25**: 253–65; and *Palliat Med* 2019; **33**: 221–31

For more on the **portrayal of microcelebrities** see *Public Culture* 2015; **27**: 137–60, and Marwick A. You may know me from YouTube: (Micro-) celebrity in social media. In: Marshall PD, Redmond SA, eds. Companion to celebrity. Chichester; Malden: Wiley Blackwell, 2016: 333–50

