

## Seeing is Engaging: Vlogs as a Tool for Patient Engagement

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Abstract:

Video blogs ('vlogs' – pronounced as one syllable) are a popular platform for conveying know-how online and can be used as a tool for patient engagement. It can be challenging to engage patients in their own care, and the unique attributes of vlogs overcome some of the barriers to engagement such as high treatment burden and a lack of the sense of community. While some clinicians may distrust social media and question its place in patient care, we present The Frey Life, one example of a patient vlog, to show how the platform models and fosters engagement, and provides the patient perspective. We discuss potential concerns regarding health vlogs, and suggest implications for physicians, researchers, and medical institutions regarding how to use patient vlogs as a resource.

Patient centeredness is a central element of high quality of care, but it is not always easy for physicians to engage patients in their own care[1]. This task can be challenging with younger patients with chronic illnesses, who may not relate to what they are told by doctors, and consequently have trouble making informed decisions about care. Recently, online videos have emerged as a popular platform for conveying knowledge and how-tos because of their convenience and accessibility for viewers. Seventy-two percent of online American adults view online videos, and the number posting videos online more than doubled from 2009 to 2013[2]. Although some physicians distrust the use of social media in patient care—in one Australian survey, 66% of physicians surveyed expressed that they were “hesitant to immerse themselves more fully in social media” due to legal concerns[3], we believe that online videos can help physicians engage patients with their own care. In this piece, we use the example of cystic fibrosis to examine how video blogs (vlog, pronounced as one syllable) may be uniquely suited to overcome barriers to patient engagement for patients with chronic illnesses, describe concerns related to such use, and offer recommendations for providers about incorporating vlogs in their clinical practice.

### **Patient Engagement in Cystic Fibrosis**

Cystic fibrosis (CF) is an inherited, chronic disease that predominantly affects the lungs and digestive system. People with CF commonly engage with the healthcare system, and also with other patients. However, there are barriers to both types of engagement. First, CF is often debilitating. In addition, it requires complex daily care, and the treatment burden may leave patients little time or energy for additional interactions with the healthcare system or the cystic fibrosis advocacy community[4,5]. An additional barrier is that because CF patients may be susceptible to acquiring infections from one another, treatment guidelines recommend that they keep at least six feet away from one another[6]. This makes it difficult to foster in-person patient communities.

### **Vlogs as Resource**

As the name suggests, vlogs are the video analogs to online journals, or blogs. Successful vlogs are often characterized by a high volume (near daily) of entries, each generally lasting 7-15 minutes. Patient vlogs chronicle patient experiences, such as demonstrating what it's like to have a coughing fit. The video sharing platform YouTube, the third most visited site on the web, is home to many notable vlogs, some of which have millions of daily views. Given the diversity of YouTube users, there is a wide range of patient vlogs on the site. A few examples are presented in Table 1.

### **The Frey Life Example**

The Frey Life is a vlog that chronicles the daily life of Mary and Peter Frey and their experiences in managing Mary's CF. Mary and Peter started the vlog in 2012, and draw an average of 15,000 viewers for their daily posts. Although the vlog covers many areas of their life, from making dinner to going to the dollar store, it has a deliberate focus on chronicling life with CF, such as posts about creative ways to conduct airway clearance therapy. The Freys interact with their viewers in two ways: 1) the videos address viewers directly, many providing answers to viewer questions posted in online comments; 2) the Freys also try to respond to those that reach out via social media. "I feel that [part of our draw is that] we are relatable," Mary says. "I understand that the foundations want the successful breakthroughs to be highlighted - the young woman with a job and kids to be on the poster—but there are patients who try really hard, and still aren't able to get 'healthy' [like myself]."

### **Overcoming Engagement Barriers**

The Frey Life exemplifies the ways vlogs exemplify one form of peer-to-peer patient support[7-9] and may help patients with CF and other chronic illnesses engage with the health system and with one another. Vlogs can provide 3 key functions:

1) Model engagement. "I'm all about do-your-treatment," Mary says, and through the vlog she models her engagement with the healthcare system and her

own treatment regimen, such as documenting her hospital stays or how she accesses and cares for her chest port to receive IV antibiotics. In demonstrating her own efforts, Frey encourages engagement and viewers have responded in kind, expressing that the videos showed that “ports aren’t that scary because I saw you do it,” and “hospital stays [don’t have to be] terrible.” Nurses have reported that patients cite her videos as an inspiration for their own compliance.

2) Foster engagement. The vlog is a platform for the Freys and other patients and families with chronic illnesses to connect with each other. Viewers not only reach out to the Freys but also respond to one another’s comments on each post. The vlog has the potential of reaching the “unreached population” of patients who are too ill to participate in outside activities and communities because vlogs present a low threshold opportunities for creating and viewing content so vloggers and viewers alike can easily interact. “In our videos,” Mary says, “we want to highlight the fact that [even though] a patient isn’t beating the odds and breaking statistics, they are still special and they are not a lesser patient.”

3) Provide Perspective. Not only can patient vlogs serve as resources for patients, they may also be educational tools for healthcare providers, especially those in training. As the proportion of adults with CF increases— more than 50% of people with CF are over 18— videos like The Frey Life provide a perspective and share insights and challenges regarding managing life outside of the hospital and adjusting to adulthood (like packing for college) that providers may not be aware of. Viewers have told Frey that their clips are being used in nursing courses. Thus vlogs give voice to patients to not only encourage and communicate with each other, but present their perspective to health care providers as well.

### **Concerns for Vlogs as Engagement Tool**

There are concerns related to the use of vlogs as a tool for patient engagement, regarding privacy, potential conflicts of interest, and oversight.

#### Privacy

Videos are inherently visual. By recording their lives and sharing their disease experiences, vloggers give up many aspects of their privacy. More so than

blog entries that speak in detail about disease experience, the visual medium adds dimension so viewers can see vloggers and their surroundings, making anonymity difficult. Vloggers, then, require different negotiations of privacy, disclosure, and boundaries to protect themselves and their information. The Freys, for example, make clear distinctions between their public and private contact information, and the degree that they are available to viewers. Privacy may also be a concern for viewers who wish to engage. Viewers may interact with vloggers and other viewers via the comments section of each video, where the information, like much else in social media, is accessible to the public, so those who wish to participate must negotiate the tension of wanting to share their similar experiences while being aware that any disclosures that they make, especially regarding their disease status, are publicly accessible.

### Conflicts of Interest & Oversight

The unregulated nature of vlogs can be a two-edged sword: allowing vloggers to connect with their audience in creative ways while also raising concerns about conflicts of interest. Successful vlogs can generate income with advertisements in two ways: through external ads played automatically before the video and internal endorsements in the videos if the vloggers have relationships with promotional products. Vloggers have little control over ads that are shown before their videos but complete control over vlog content. The Freys, for example, receive payment from sponsored ads shown on YouTube. They also occasionally devote screen time to discuss and promote products and companies that they have relationships with. In one video, for example, the couple discusses their relationship with a company that helps patients with medical debt. In another, they prepare dinner using a meal kit from the company Hello Fresh. These endorsements raise questions regarding potential conflicts of interest, and how much information bloggers and vloggers are ethically required to disclose.

Beyond advertising, patient-directed vlogs also raise questions of oversight for the information that is presented and the evidence-base for medical claims made

or advice given in the videos. The personal, and anecdotal stories conveyed in vlogs are both a strength and weakness of this platform.

## **Implications**

While it may be tempting to dismiss vlogs as yet another social media fad, web videos are how US adults increasingly obtain content. According to Google, YouTube reaches more 18- to 49-year-olds in America than any U.S. cable network[10,11]. Though much of the limited literature on social media in healthcare, especially YouTube, has focused on YouTube as a one-sided, rather than dynamic, information source for patients or medical students[12-14], physicians that take care of young patients should be reminded that new technology is an important element of the lives of this generation. Vlogs like the Frey Life provide a novel way to get these patients' attention yet they have not been systematically incorporated into clinical practice and only a few published papers have considered their use[15-17]. The limited, descriptive studies on the topic emphasize the medium's strength as a tool that offers support and builds community among vloggers and viewers.

Given the potential power of vlogs, we recommend that physicians, particularly those caring for people with specific chronic conditions, familiarize themselves with a few key vloggers. They should recognize vlogs as a window into the patient perspective, and know how to discuss or recommend the resource to patients who may benefit from the kind of engagement provided. Similarly, we think that medical institutions, including advocacy groups, foundations, medical societies and hospitals, should recognize the influence of patient vlogs and help patients and providers navigate this resource. Just as some news sources are more reliable than others, organizations could curate lists of vlogs to help patients separate the good from the bad and highlight those that should be promoted for their value to patients and providers. Such involvement online would also keep physicians aware of myths or inaccurate information being presented to a wide audience so they may anticipate how to educate patients or address their questions.

Physicians should make patients aware of the availability of vlogs as a helpful resource. Beyond that, they could also encourage patients to view vlogs as a means to convey the patients' own experiences and challenges to providers, especially for younger patients for whom the technology is more familiar. The interactive nature of vlogs fosters the sense of participation with very low barriers to entry and such ease and community that vlogs can provide are especially important for patient whose illnesses keep them from such engagement outside of the home.

The rise of patient vlogs in the last decade raises many questions and the need for an evidence base to support this platform. Researchers could help physicians and professional societies determine what messages are being sent by patient vlogs, how these messages relate to those by the medical institutions, and whether vlogs point to unmet patient needs institutions have overlooked. While the landscape of social media tools available for patient engagement appears to be constantly changing, being able to engage patients with chronic illnesses on platforms they are already familiar with makes the effort worthwhile.

**Conflict of Interest:** Mary and Peter Frey receive payment from YouTube for their vlog posts, depending on page views. The other authors have no other conflicts of interest to disclose.



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Table 1: Examples of notable patient vlogs

Vlog Name	Description	Disease	Subscribers
<b>The Frey Life</b> ( <a href="https://www.youtube.com/freylife">youtube.com/freylife</a> )	Young married couple Mary and Peter chronicle their daily life of faith, humor, and managing Mary's chronic illness.	Cystic fibrosis	79,000
<b>Zoella</b> ( <a href="https://www.youtube.com/zoella">youtube.com/zoella</a> )	Though Zoella predominantly vlogs (and blogs) about fashion and beauty, she has also shared her experiences with anxiety and panic attacks in her videos.	Anxiety and panic attacks	11,120,487
<b>Jonny Benjamin 1</b> ( <a href="https://www.youtube.com/user/johnjusthuman/">https://www.youtube.com/user/johnjusthuman/</a> )	Mental health advocate Jonny documents his personal journey and recovery with mental illness.	Schizoaffective disorder	10,007
<b>Charlotte Eades</b> ( <a href="https://www.youtube.com/channel/UC6bE4OSCx99n7pF3vtZQMrw">https://www.youtube.com/channel/UC6bE4OSCx99n7pF3vtZQMrw</a> )	Charlotte Eades was a British teenager who vlogged about her life with brain cancer. After her death, her mother and brother continued the vlog as a way to preserve her memory and discuss what it's like being a loved one of a cancer patient.	Cancer	4,059