

How to Peddle Hope: An Analysis of YouTube Patient Testimonials of Unproven Stem Cell Treatments

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Providers capitalize on patient testimonials to market unproven stem cell treatments (SCTs). We evaluated 159 YouTube videos and found patients discussed health improvements (91.2%), praised providers (53.5%), and recommended SCTs (28.9%). In over a third of the videos, providers posed questions to patients, thereby directing narratives and making them a powerful marketing tool.

INTRODUCTION

Unproven stem cell treatments (SCTs) are marketed globally to consumers via the internet and have resulted in physical, financial, and emotional injuries to patients (Bauer et al., 2018). Clinics are found all over the world, including those in highly regulated countries such as the US, Australia, Japan, and the UK (Berger et al., 2016). Providers often use misleading claims, hard sell promotional techniques, and base efficacy claims on patient testimonials.

Knowing the marketing practices of providers is key to understanding their business models and developing strategies to counter misinformation. Interventions that improve health literacy, patient-physician communication, and counseling might be more suitable countermeasures because the effectiveness of strategies to regulate the industry or discipline bad actors remains questionable (Knoefler, 2018a; Shapiro et al., 2019). The media has been utilized by providers who appear with experts or celebrities, thereby adding credibility to their practice (Knoefler, 2018b). Perhaps the most potent marketing tool is the use of testimonials where patients share their medical struggle and therapeutic journey. Patient narratives are

powerful messages because other patients can relate to the story and sympathize with the storyteller (Hinyard and Kreuter, 2007). People find that “a person like you” is one of the most credible sources of information (Edelman, 2018), and narratives have been shown to increase belief and message uptake more than statistical information (Greene and Brinn, 2003).

Patient testimonials of unproven SCTs are found on clinic websites, blogs, social media sites, and are uploaded onto YouTube. Video testimonials may be particularly persuasive. Not only are they able to communicate messages to individuals with varied health literacy levels, but internet users have been shown to identify more strongly, and rate products more favorably, with audio/video testimonials as opposed to text or picture-based testimonials (Appiah, 2006). With over 1 billion users, YouTube has greater reach than any television network and presents a formidable platform to market unproven SCTs.

To date, no study has examined patient testimonials and provider infomercials of unproven SCTs on YouTube. In this study, we examined the content of 159 YouTube videos of patient testimonials and provider

infomercials for unproven SCTs addressing five major diseases and injuries, including amyotrophic lateral sclerosis (ALS), cerebral palsy (CP), multiple sclerosis (MS), Parkinson disease (PD), and spinal cord injury (SCI).

Patient Testimonials of SCTs on YouTube

We identified 159 videos (7 ALS, 39 CP, 37 MS, 37 PD, and 39 SCI) totaling 563,842 views (ranging from 29 to 93,156 views) with an average of 3,546 views/video. Videos ranged from 32 s to 26:56 min. A total of 101,295 subscribers (ranging from 1 to 2,047 subscribers) were found in 157 videos. The three most highly viewed YouTube videos published by the International Society for Stem Cell Research (averaging 1,030 views/video) were viewed less than the average among those in our dataset although some SCT videos had views comparable with those published by the California Institute of Regenerative Medicine (averaging 16,792 views/video).

Video were published from 2007 to 2014, with 53.3% (N = 80) published in 2013–2014 (Supplemental Information). One study limitation is that our YouTube searches based on relevance resulted in capturing older videos. But among the 159 videos in

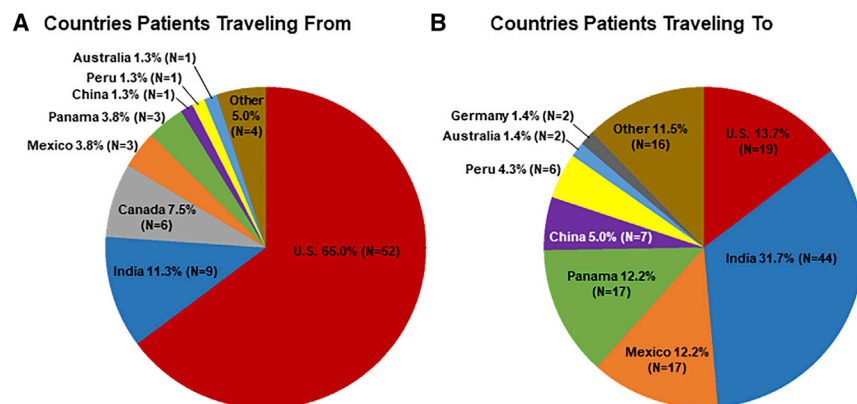


Figure 1. Countries Mentioned by Patients
(A) Countries patients travelling from.
(B) Countries patients travelling to.

our dataset, only 9 links were inactive in December 2018, indicating that most remain active. Other than 3 videos where the patient was the publisher, 98.7% (N = 156) of videos were published by clinics providing unproven SCTs. Seven clinics published 6 or more videos, constituting 78.8% (N = 123) of videos in our dataset.

Patient testimonials, where the patient or another person shares the patient's narrative, constituted 92.5% (N = 147) of videos. A few videos included a combination of a patient testimonial with an advertisement. Twelve videos were an infomercial published by a SCT provider containing no patient testimonials (see [Supplemental Information](#)). Patients were visually present in 98.6% of testimonials, in some cases via photos. In 73.5% (N = 108) of videos, the patient was an adult. In 26.5% (N = 39) of videos, the patient was a child. Children as patients were seen in all but one CP video. Additional people including parents, partners, friends, and other family were found in 47.6% of videos.

While SCT providers published most of the videos, the providers themselves appeared in 53.1% of videos. In 44.9% of videos, providers asked specific questions to patients. Provider-prompted questions were heard verbally (34.0%), either with/

without their presence in the video, or seen as video subtitles (12.9%). Examples of provider prompts included questions about the patient's health issues, why they chose to undertake a SCT, cleanliness of the facilities, or health benefits post treatment among others.

Of the 80 videos where patients mentioned their country of origin, the majority were from the US followed by India and Canada ([Figure 1A](#)). In 139 videos, patients reported the SCT clinic location with India having the most, followed by the US and Mexico ([Figure 1B](#)). These results indicate that patients travel from and to different countries.

Patients described various features about the SCTs they received (see [Table S2](#) for Codebook for YouTube Video and Audio Analysis). In about a quarter of the videos, patients mentioned a stem cell source, including adult, bone marrow-derived, umbilical, fat, placental, or fetal. SCT administration procedures were reported in 12% (N = 19) of videos, including intrathecally, subcutaneously, intravenously, or by injection. Patients mentioned risks in 10.1% (N = 16) of videos, all of which were underemphasized, except for one case. Patients mentioned benefits in 95% (N = 151) of videos which, in

all but two cases, were overemphasized. Costs of SCTs were mentioned in 5% (N = 8) of videos and that providers can treat additional conditions in 16.3% (N = 26) of videos. Patients mentioned undergoing two treatments in 23.3% (N = 37) of videos and three or more treatments in 8.8% (N = 14) of videos, with one patient reporting having had eight treatments. SCTs were described as "experimental or controversial" (2.5%, N = 4) or "alternative" (1.3%, N = 2), but none were described as "unproven." Only one patient (0.6%) mentioned that the intervention had undergone ethics or regulatory approval, and 4.4% (N = 7) of patients mentioned that the treatment was based on previous research or publications.

The Power of Patient Narratives

We performed a qualitative analysis of the video, audio, and transcribed voices identifying seven major themes ([Table 1](#) and see [Table S3](#) for example quotes).

Nearly all videos generally described the benefits of SCTs as improving health, quality of life, or energy. Specific benefits included increased appetite, weight gain, strength, movement, flexibility, sensation, circulation, verbal abilities, cognition, physical appearance, vision, and urination, as well as improving shaking/tremors, seizures, pain, and drooling. In 58% of cases, patients acted out scenes, sometimes before/after scenes, showcasing health benefits such as improved mobility, decreased stiffness, or increased flexibility by getting out of bed, clapping, grabbing objects, sitting up, and performing exercises among others.

Patients or others offering praise and showing gratitude to the clinic, provider, staff, or SCTs more generally was a dominant theme. Words of admiration, commendation, approval, compliment, and salvation were routinely used by patients, and providers were described as



Table 1. Description of Major Themes of Patient Testimonials on YouTube

Theme	Description	Frequency, % (N)
Benefits	An improvement in overall health, quality of life, or specific improvement	91.2 (145)
Praise	Patients/others offer praise for the treatment, provider, or SCT	53.5 (85)
Choice	Patient/others explain the reason for choosing a specific clinic	34.0 (54)
Recommendation	Patient or provider recommends treatment to others	28.9 (46)
Hope	Patient explains that the treatment, provider, or the clinic offered hope	26.4 (42)
Procedure	Patient describes the procedure (step by step) or describes the procedure as low or no risk	24.5 (39)
Motivation	Patient describes why they sought an SCT	22.6 (36)

professional, knowledgeable, experienced, warm, kind, caring, compassionate, embracing, tremendous, fantastic, easy to talk with, and pleasant. Some patients made reference to their prayers being answered, being blessed, or owing their life to the providers and staff. In many cases where patients conveyed praise and gratitude, positive emotions of smiling, giving a high-five, or providers placing their hand on parents or patients were seen. Scenes of heightened emotion, such as crying, about to cry, appearing distressed, stuttering, or being unable to speak were seen in 16% of videos. Such heightened emotions were expressed in relation to patients or families reflecting back on their situation prior to receiving the SCT.

Over a quarter of the videos explained that the provider, clinic, or the SCT offered hope. Patients explained their motivation for seeking a SCT after exhausting other medical options, having no alternatives left, fearing disease progression, side effects or worsening of symptoms, avoiding the need to increase medication, and wanting to gain control over their condition. Several patients were reflecting on the lack of hope they experienced with respect to their medical care before reaching the stem cell clinic.

In several cases, patients explained their choice of specific clinics based on advertisements, research, or a recommendation. And perhaps the most powerful summative message was a recommendation of the SCT by the patient or provider to others.

Limited Audio and Video Sophistication

Overall, the videos were limited in video and audio sophistication. Few videos had different camera angles or cuts, and many appeared as a “talking head.” Some videos were filmed in high quality and had good lighting while others seemed considerably less polished. Over half (57.9%) of the videos contained acted out scenes. Interestingly, videos of CP (87.2%) and SCI (74.4%), where movement improvements might be more easily noticeable, had more acted scenes compared with PD (51.4%) and MS (21.6%) patient videos. Special visual light effects, including flashes, scrolling words, or changing word sizes, appeared in 96.2% (N = 153) of videos. For example, a patient explaining 20% increased mobility would flash “20%.” Instrumental music without words played in the background of 66.7% (N = 106) of videos, allowing voices to be heard. English was spoken in 75.5% (N = 117) of videos, and

25.2% (N = 39) of videos were spoken in another language with English subtitles.

Influential Marketing

Narratives, especially video-based testimonials, are likely to influence intentions, beliefs, and risk perceptions and have an impact on treatment choices (Appiah, 2006; Hinyard and Kreuter, 2007). Our study indicates that SCT patient testimonials on YouTube may be a potent marketing tool. A December 2018 search of the most highly viewed stem cell videos on YouTube resulted in a patient testimonial being the third highest, receiving over 2 million views. This Joe Rogan Experience podcast featured Mel Gibson and a provider who together discussed a SCT given to Gibson’s father. By producing the video and prompting questions, providers can avoid conflicting or damaging messages and highlight messages of hope, praise, and improvements from SCTs (Michie et al., 2018). Compared with educational videos about SCTs from reputable scientific organizations, videos featuring patient testimonials are likely to have a wider reach and significant impact on influencing health behavior.

The positive nature of patient experiences showcased in testimonials is not surprising given that the majority are published by providers, likely as a marketing strategy. Exploring the veracity of the claims made was beyond the scope of this research. More importantly, the findings illustrate the ways in which patient testimonials could be used to provide an accurate and balanced representation about SCTs to the interested public. This is important given that there is limited comprehensive, online education on unproven SCTs (Master et al., 2014). These traditional text-based patient booklets and websites depend on conveying fact-based information about risks, among other information, to patients requiring them to make



rational choices. While helpful to some, these booklets are unlikely to appeal to the emotional side of reasoning when making health care decisions (Kahneman, 2011). Patient testimonials should be used to develop sophisticated health literacy tools to counter the hype and misinformed messages about unproven SCTs. Perhaps a patient testimonial where the outcome was not as had been expected could better convey the risks inherent to unproven SCTs and the spurious business practices of some providers. However, care should be taken not to fight anecdote with anecdote, and narrative-based strategies would need to be factual and accompanied by other modalities including discussions with physicians, as well as expanded options for patients to access clinical trials or medically innovative care. Adopting multiple approaches, including patient education, enhancing patient treatment options, and regulatory oversight, are required to make a significant dent in reducing the number of clinics providing unproven SCTs.

SUPPLEMENTAL INFORMATION

Supplemental Information can be found online at <https://doi.org/10.1016/j.stemcr.2019.05.009>.

AUTHOR CONTRIBUTIONS

Z.M., T.C., and A.Z. made substantial contributions to the conception and design of

the project. B.H., A.R.P., D.P., and Z.M. made substantial contributions to the collection and analysis of data. Z.M. wrote the first draft of the manuscript and all authors revised the manuscript for important intellectual content. All authors approved the final version to be published.

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