

Synthetic phosphoethanolamine: the "cancer pill" and the role of users on YouTube

Eduardo Augusto de Souza Barreto Rosario¹

Museu da Vida / Casa de Oswaldo Cruz / Fiocruz, Rio de Janeiro, Brazil

Luís Amorim

Museu da Vida / Casa de Oswaldo Cruz / Fiocruz, Rio de Janeiro, Brazil

Honorary Research Associate (STS/University College London), UK

Marina Ramalho

Museu da Vida / Casa de Oswaldo Cruz / Fiocruz, Rio de Janeiro, Brazil

Introduction

According to data from the World Health Organization (WHO), by the year 2025, the number of cancer cases could reach more than 20 million diagnoses per year. The development of more effective cancer treatments is one of the significant challenges of science and one of the crucial public health problems in the world.

Research into new drugs against the disease, therefore, develops amidst many expectations. Various treatment options are proposed periodically, including methods and substances not recognized by science. The lack of scientific basis, however, does not prevent these alternatives from gaining popularity.

In 2015, phosphoethanolamine gained notoriety in Brazil as another possible option to treat cancer. The emphasis on the substance was enhanced by the fact that it was developed in the premises of the Institute of Chemistry of the University of São Paulo (USP), campus of São Carlos (SP), by researchers linked to the institution.

The objective of this work is to analyze the videos on synthetic phosphoethanolamine published and most viewed on YouTube, selected through the search of keywords that refer to the substance, outlining a panorama on how the subject is approached.

Phosphoethanolamine: trajectory and conflicts between science, justice, politics, and society

In 2015, the Brazilian media reported cases of patients who were fighting in court for the right to use phosphoethanolamine to treat cancer, even if the substance was not recognized as a medicine by the official health agencies. The substance was experimentally consumed at least since the 1990s when it was first produced and distributed in capsules by chemist Gilberto Chierice, a retired professor at the University of São Paulo in São Carlos. According to the researcher, the beginning of this experimental treatment would have occurred through an agreement between USP and

¹ nedc.fiocruz@gmail.com

Amaral Carvalho Hospital, in Jaú (SP), following rules of the Ministry of Health (ESTEVEES, 2016).

The Chierice synthesis method would be a cheaper and more efficient way to obtain phosphoethanolamine compared to traditional methods. Several patients reported improvements and even remission of cancer attributed to the use of the compound.

In June 2014, months after Chierice's retirement, an ordinance from the USP rectorry banned the production and distribution within the university of drugs that had not registered with Anvisa, such as phosphoethanolamine. The interruption of supply marked the beginning of immense popular pressure, rarely seen in Brazil around a scientific theme, which changed the course of discussions and research on synthetic phosphoethanolamine.

Patients obtained injunctions in the court that required USP to make phosphoethanolamine available again. Then the mobilization reached the National Congress, through a bill, approved by the Chamber and Senate and sanctioned by the presidency of the Republic, even against the recommendations of Anvisa - National Agency of Sanitary Surveillance. The bill (4639/2016) authorized "the production and use of synthetic phosphoethanolamine, provided the patient proves that he has cancer and signs a consent term" (ESTEVEES, 2016, p.37).

The federal government released a budget of 10 million Brazilian reais for clinical trials with phosphoethanolamine, which gained an advantage compared to other substances that also applied for registration with Anvisa (ESTEVEES, 2016, p.38).

The controversy and controversy around phosphoethanolamine, therefore, involve clashes between society; science (questioned in its legitimating action in health promotion); the Legislative, Executive and Judicial branches; and also, as Esteves (2016) portrays, attacks on the pharmaceutical industry, accused of boycotting drugs that effectively cure cancer, and suspicions against the media, classified as "partial" or classified as "scientific illiterate."

Scientific communication on YouTube and the "producers"

Studying the repercussion of phosphoethanolamine on YouTube allows us to broaden our knowledge about scientific communication on the Internet. This aspect is important in the task of elaborating messages to an audience with gaps in their scientific education, but increasingly connected, especially through social media.

Erviti and Stengler study, published in the Journal of Science Communication, analyzed scientific communication through online videos, from the main professional scientific content channels created in the UK and published on YouTube. The researchers interviewed those responsible for the channels, who highlighted characteristics of this type of content: the ability of the videos to be incorporated in other sites and also shared in other social media, expanding the reach and profile of the public; and the significant presence of "user-producers" ("producers"), which favor the construction of a sense of community around the channels, building loyalty and broadening the audience (ERVITI; STENGLER, 2016).

The presence of "user-producers" is also pointed out by Reale and Martyniuk in work on science communication on YouTube presented at the XXXIX Brazilian Congress of Communication Sciences:

Since its beginning in 2005, the site has made it possible to access network video and allow users to also become content generators. It is a collaborative platform in which any user can post content (REALE; MARTYNIUK, 2016, p. 6).

According to the researchers, the autonomy in the production of content in the platform is facilitated by the presence of own editing tools: a characteristic that allows to overcome greater requirements of professional qualification: "With this, the domain of capture, edition and publication of the videos is in the hands of the users, not requiring specific training for this type of action"(REALE; MARTYNIUK, 2016, p. 6). Autonomy and interactivity are also highlighted in relation to the way it interacts with videos:

The visitor is invited to get involved by subscribing to the channels, following the contents and continuing the discussion in the comments and other social networks, which allow the generation of links between users. [...] It is not only the number of clicks that prevails but the ability of content to be engaged and maintain connections after its publication. The content is directed and invokes a constant exchange, thus cultivating communities. (REALE; MARTYNIUK, 2016, p. 7)

The aforementioned features - a stimulus to user-producer participation, production autonomy and interaction with content, and community engagement - help explain YouTube's potential as a means of science communication.

Scientific dissemination in digital networks is a possible way to foster communication of science, using the potential of the digital environment as a means of integration, socialization, and exchanges of experience, information, and knowledge. It works to promote a new scientific culture in which dialogue with the population happens naturally. The YouTube platform has the potential to fulfill this role, especially with young people, since the consumption of video on the Internet has grown exponentially in recent years. (REALE; MARTYNIUK, 2016, p. 6)

Method

The study that originated this paper used YouTube's own search system to search for four keywords: "phosphoethanolamine", "cancer pill", "Chierice" and "phospho". The choice of these terms considered words in evidence linked to the research object and that could provide more direct results.

Using as a filter the number of views, the 30 most watched videos were selected in each one of the searched terms, which allowed the construction of a relevant sample for the study. The number of views is understood as a measure of importance and repercussion of the videos.

After eliminating videos that appeared at the same time in different keywords, as well as videos without linking to the theme, the corpus was established in 95 videos. These were made available on 48 different channels, and were published between August 26, 2015, and October 6, 2016. This chronological interval was a consequence of the search by the number of views in search of the keywords. The number of views was determined on October 11, 2016, marking the beginning of the survey.

A table has been created with the following categories: video title; classification of the title (descriptive or opinionated); number of views; search position for each keyword (by number of views); time (duration); publication date; channel name; classification of the video as to the type of content (CGP - content generated by professionals or CGU - content generated by the user); audiovisual genre (scientist testimonial, patient testimonial, politician testimonial, poll, Television news story, auditorium program, radio

program, instructional video, videoblog - science communicator, videoblog - layman); presence of scientific controversy, presence of controversy, presence of the scientist, presence of characters / citizens; scientific contextualization; and description of the video.

Video classification for content type was included as a category of analysis because of the importance of investigating the relevance and impact of user input versus more traditional media companies. And, from the study of this case, obtain indications about the role of these actors in the science communication in general.

This classification of online videos is in line with the concept of Jin Kim (2012, p.53, apud ERVITI and STENGLER, 2016): content generated by users (CGU) and content generated by professionals (CGP). Kim argues that YouTube is no longer an amateur tool (CGU) and says that more and more contents are professional generated, and that YouTube has been increasingly influenced by "traditional agents" like TV broadcasters. However, Welbourne and Grant (2015), in content analysis work on 390 online science communication videos, found that content generated by users is significantly more popular in comparison to CGP. The researchers studied the popularity of videos by looking at factors such as the number of views, number of subscribers, age of the channel, the number of videos created, the size and pace of content. CGU's popularity, they say, is related to the presence of a regular scientific broadcaster as a host; and with the rate of information transmission: the faster it is, the faster the number of views increases.

The categorization of the video regarding the audiovisual genre investigated the influence of the format in the construction of different perceptions of the public on the theme. For Barry Langford (apud ANDRADE, 2015, p.1-2), audiovisual genres "offer a method of classification that establishes common and historical traits among productions. For those who produce, the genres offer formulas that propose directing to a production".

After describing the videos, we distinguished 10 audiovisual genres: "scientist testimonial", "patient testimonial", "politician testimonial", "poll", "television news story", "auditorium program", "radio program", "Instructional video", "videoblog – science communicator", "videoblog - layman".

The categories "Scientist testimonial", "Patient testimonial", and "Politician testimonial" identified the videos that presented as main and prominent voices, respectively scientists, patients and politicians, in situations without media mediation, speaking face-to-face to groups or class entities, in situations such as lectures, commissions and inquiries, in open explanations, answering or not to questions posed by those present at the time; as well as spontaneous video recordings of these voices, posted on YouTube in isolation, in the sense that they do not present sequence or periodicity context (a characteristic that would classify these videos as "videoblogs").

The "Poll" category defines videos that only present questions about phosphoethanolamine to the audience, encouraging participation through comments in the video itself or other media (other social media or e-mail).

In the category "Television News Story", the videos should present elements of this telejournalism product, such as reporter presence in passing or off, lettering, insertion of sound (interview), videography (art): elements grouped through image editing.

The "Auditorium Program" category featured videos in which the figures of the presenter and auditorium appear prominently. This category provides for a dynamic alternation of participation between main guests of the program and present in the audience, as well as elements such as humor and spontaneity in driving the attraction. The "Radio Program" category includes videos that record the studio environment (with the presence of the speaker and occasional guests) in initially radio broadcasts. In addition, there are the specific characteristics of the radio, such as the essentially personal character: even though it is a medium of mass, the speaker addresses each listener in a tone of complicity. This particularity of the medium is noticeable in the videos and thus, once again, justifies the categorization.

The category "Instructional Video" addresses the issue of using video as a tool for distance education. The videos in this category have an essentially didactic purpose. The focus is to explain the characteristics of the substance, theories and scientific experiments that support or not the possibility of the compound acting against cancer

The categories "Videoblog - science communicator" and "Videoblog - layman" represent the audiovisual genre that may be more in tune with the original YouTube proposal, "Broadcast Yourself," representing a response to a more direct appeal to the user in audiovisual production, independently and informally. To deepen this argument, we start with the etymology of "Videoblog": the union of the word "video" with the English term "web log" (or its contraction blog), which means "network registration". Thus, we understand that "Videoblog" (also called "Vlog") characterizes content produced continuously, in continuous episodes (such as a diary), using the video format.

It is possible to connect certain audiovisual genres to the categorization of content type: CGP or CGU. This link is evident, for example, in the genres "Television news story", "Auditorium program" and "Radio program", illustrates CGP content; and in the genres "videoblog" (both "science communicator" and "layman"), representative of CGU.

Results and discussion

In this article, we will focus mainly on the impact of the "producers", as we have noticed their enormous importance for the debate about phosphoethanolamine on YouTube.

In the analysis of the videos concerning the type of content, we verified that among the 95 videos of the corpus, 50 are CGP and 45, CGU. Although CGP videos are more numerous, their total number of views (1,462,052) is well below CGU video views (3,054,754) - less than half. This result is in line with the study by Welbourne and Grant (2015), who analyzed content from 390 online scientific communication videos and found that CGU videos were more popular, although there are more CGP videos available. In this analysis we identify videos that fit together in more than one category.

In the classification by audiovisual genres, we find the distribution contained in table 1 below:

Relationship between video categories by audiovisual genre and number of views		
Category	Number of Videos	Number of views

Videoblog – science communicator	12	1.649.998
Videoblog - layman	15	946.697
Television news story	18	771.389
Auditorium program	10	484.269
Scientist testimonial	26	290.019
Instructional video	5	212.309
Politician testimonial	4	161.948
Patient testimonial	5	110.358
Radio program	3	61.925
Poll	1	28.860

Table 1: Relationship between video categories by audiovisual genre and number of views

When we considered only the 10 videos with the highest number of views (as shown in table 2), we observed: presence of 5 videos from the category "Videoblog - science communicator" (with a total of 1,268,055 views); 2 videos "Videoblog - layman" (380,646); 2 videos "Auditorium Program" (344,938); and 1 video "Television news story" (285,812).

Title	YouTube Channel	Number of views	Category
Fosfoetanolamina Nerdologia 107	Nerdologia	470.788	Videoblog – science communicator
A USP, o câncer, e a cura (#Pirula 117.1)	Canal do Pirula	409.309	Videoblog – science communicator
Brasileiro Descobre Cura do Câncer e é Preso REPORTAGEM	Theodrall	285.812	Television news story
Ratinho e a FOSFO!! (Toma Viadão!!)	Nando Moura	238.165	Videoblog - layman
Programa do Ratinho (24/02/16) - Ratinho desabafa sobre câncer e chora	Programa do Ratinho	231.476	Auditorium program
13 respostas sobre a FOSFOETANOLAMINA (#Pirula 117.2)	Canal do Pirula	152.728	Videoblog – science communicator
M.E.R.D.A. e a fosfoetanolamina	Nando Moura	142.481	Videoblog - layman
Esclarecimentos sobre a fosfoetanolamina	Drauzio Varella	123.999	Videoblog – science communicator

Programa do Ratinho (24/02/16) - Pílula cura o câncer - Verdade ou mentira?	Programa do Ratinho	113.462	Auditorium program
Fosfoetanolamina, Ratinho e Samarco (#Pirula 133.1)	Canal do Pirula	111231	Videoblog – science communicator

Table 2: Ten videos with the highest number of views

Thus, in this subgroup of 10 videos, once again we confirm the relevance of user generated content (CGU), represented by the categories "Videoblog - science communicator" and "Videoblog - layman". Also in this group, CGU videos outnumber CGP videos ("auditorium program" and "television news story") in quantity and in views.

Attention was drawn to the strength of the Videoblog tool in front of traditional media: a tool used by both scientific and lay disseminators. The genre "Videoblog - science communicator" appears first in number of views: it is present in 12 videos, with 1,649,998 views; and the genre "Videoblog - layman" comes next in this ranking: it classifies 15 videos, with 946,697 views. In addition, the views of these two categories reach 2,596,695 (in 27 videos): 57.48% of the views of the corpus.

Meanwhile, audiovisual genres representative of CGP - "Television news story", "Auditorium program" and "Radio program" - have 31 videos and 1,317,583 views: 29.17% of the total. The audience for videoblogs, therefore, was much larger compared to genres that represent production of traditional media companies.

Another highlight was the comparison between the categories "Videoblog - science communicator" and "Scientist testimonial". The category "Videoblog - science communicator", present in 12 videos, appears ahead in number of views of the category "Scientist testimonial", present in 26 videos. It is necessary to consider the differences between formats, both from the aesthetic and content points of view. However, taking into account the number of views regarding the number of videos in each category, it is important to note how the science communication through the videoblog tool played an important role, obtaining a larger audience than the figure of the scientist speaking directly about the theme. The role of science communication through formats that are friendly to the lay public can not, therefore, be ignored.

Videos classified as CGU, in addition to frequently citing other user channels, also use professionally generated content at various times to base favorable or unfavorable arguments on phosphoethanolamine. At the same time, it was also possible to watch Television news stories (CGP representatives) using user-generated content on YouTube, mainly testimonials from patients and members of the Chierice team.

This finding could indicate that CGU contents have broadened the debate initiated by traditional media companies and, at times, also seem to have influenced professional content. This exchange seems to confirm the suggestion by Obrist et al. (apud Erviti and Stengler, 2016) that the narrative by means of videos continues strong and that the line between traditional television consumption and online video is increasingly tenuous.

Final considerations

The research that originated this article investigated how the debate concerning phosphoethanolamine were reflected in online videos published on YouTube. By mobilizing different actors - as a society, political environment and scientific community - the substance attracted attention on scientific practice and its importance in everyday life. With this, we see the opportunity to broaden the understanding on how science communication can be positioned in order to integrate science and society.

Given the complexity of this scenario, we have chosen to analyze the repercussion of the theme in a rising media, such as the Internet, and in a transmediatic space such as YouTube. This social media presents a growing audience, while motivating renewal in traditional media: media that are also present on the platform through official channels.

The study revealed the importance of user participation on YouTube in the repercussion of synthetic phosphoethanolamine. Videoblog as a tool for science communicator achieved a greater audience in relation to traditional media and represented the only attempt to balance the debate by serving as a vehicle for arguments that questioned the therapeutic potential of the substance: a clearly minority position in the corpus. The superior performance in views of the category "Videoblog - science communication", compared to the category "Scientist testimonial", also reinforced the efficiency perception of videoblog. These results suggest important implications for science communication, as it is signaled, from the case of phosphoethanolamine, that it is possible to establish an efficient connection with the public without relying on the infrastructure and resources of traditional media companies.

References

ANDRADE, C. L. R.. **Vlog como gênero da indústria audiovisual**. In: XXXVIII Congresso Brasileiro de Ciências da Comunicação, 2015, Rio de Janeiro. Disponível em: <<http://portalintercom.org.br/anais/nacional2015/resumos/R10-2096-1.pdf>>. Acesso em: 24 abr. 2017.

ERVITI, M. d. C.; STENGLER, E.. **Online science videos: An exploratory study with major professional content providers in the United Kingdom**. Journal of Science Communication, 2016. Disponível em: <https://jcom.sissa.it/archive/15/06/JCOM_1506_2016_A06>. Acesso em: 24 abr. 2017.

ESTEVES, Bernardo. **A Panacéia - ascensão e queda da Pílula do Câncer**. Revista Piauí, nº 120, p.30-40, setembro de 2016.

MINISTÉRIO DA SAÚDE, Instituto Nacional de Câncer. **Estimativa 2016: Incidência de Câncer no Brasil**. INCA, Rio de Janeiro. 2015.

REALE, M. V.; MARTYNIUK, V. L.. **Divulgação Científica no YouTube: a construção de sentido de pesquisadores nerds comunicando ciência**. In: XXXIX Congresso Brasileiro de Ciências da Comunicação, 2016, São Paulo. Disponível em: <<http://portalintercom.org.br/anais/nacional2016/resumos/R11-0897-1.pdf>>. Acesso em 20 nov. 2017.

WELBOURNE, D. J., e GRANT, W. J. (2015). 'Science communication on YouTube: Factors that affect channel and video popularity'. Public Understanding of Science, 2015. Disponível em: <<http://pus.sagepub.com/content/early/2015/02/18/0963662515572068.full.pdf+html>>. Acesso em 27 abr. 2018.