Understanding the Social Mechanism of Cancer Misinformation Spread on YouTube and Lessons Learned: Infodemiological Study

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Excerpts

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Complex Contagion of Health Behaviors in Social Media

Adoption of behaviors frequently manifests as a complex contagion: the spread of collective behaviors requiring contact with multiple sources of activation [18]. Complex contagion occurs when social reinforcement influences the transmission of behaviors, beliefs, and attitudes. Unlike simple contagion, in which exposure results in immediate transmission, complex contagion requires social legitimation, credibility, and behavioral complementarity due to uncertainty [18,19]. Studies found that adopting health-related behaviors, such as smoking, exercise, and antivaccine beliefs, are proven to follow the complex contagion mechanism [20-22].

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Studies have discovered that social media is one of the perfect environments for observing complex contagion [23-25]. Clustered communities in social media serve as peer-to-peer communication and information dissemination networks [25-27]. Social media research frequently reveals patterns of shared exposure to common stimuli [27], but not all patterns are identical.

- If complex contagion is viewed as the direct link between social media users, it is social cohesion that binds people together in a networked group, often seen in Facebook [28,29].
- If the contagion is based on exposure between individuals, regardless of connection between users, then it is contagion via the network structure that enables access to the same source of exposure, typically found in YouTube through its recommendation algorithm [30,31].
- The continuous flow of relevant and engaging YouTube videos, as well as the linking of video content via YouTube's recommendation system [17,32], creates the environment conducive to social reinforcement, a necessary requirement for complex contagion.

Methods

YouTube Data Collection

... We used Google's YouTube application programming interface (API) to retrieve a list of search query and recommended videos [39] by using a Python program. The API provides the meta information, such as a video title, channel name, the date and time of upload, and number of views, likes, and comments

Our data collection strategy was as follows.

1. we used the term "fenbendazole" in Korean to download the list of the videos from the YouTube API.
2. videos were included in the analysis if the video views were more than 50,000, uploaded between September 2019 and September 2020. The number 50,000 has been frequently used in the literature to filter relevant and popular YouTube videos [41,42].
3. we compiled a list of the top 10 recommended videos for each video we searched. ...
    - The top 10 is the number that has been used in the literature for examining recommendation effects [43,44]. Note that this list was not the same list as our API search query for fenbendazole. YouTube's recommendation algorithm analyzes viewers' data regarding their viewing habits and uses the data to make recommendations. This does not imply that the YouTube API reflects the preferences of the API key holder. The YouTube API returns the data to the developer that matches the query parameter, such as video, channel, and playlist [39].
    - It is known that the YouTube API offers results based on popularity rather than individual user desires [45].

A variety of techniques were used to decipher the ... network.

First, the timeline of uploaded videos was analyzed, and the influencers, in terms of

- view count and
- location in the core of the network,

were identified through the network analysis index, **k-core**.

Second, network diagrams were drawn in order to locate the influencers in the network.

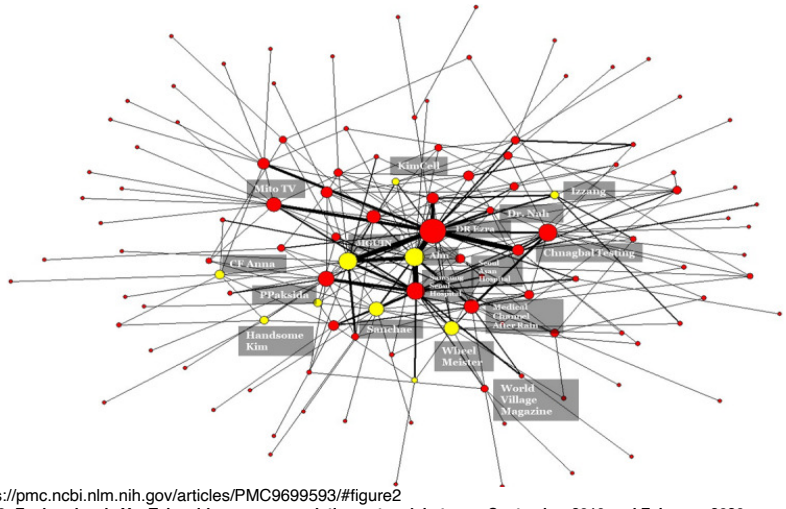
- We used the **edge list format** to convert the list of video searches and recommendations into a network matrix of relational data.
- In this process, duplicate videos were counted as the value of network ties.
- The **NetDraw program** (Analytic Technologies) was then used to draw and to analyze the network data [46].
- Although the analysis unit of the collected data was a video, we depicted the network diagram at the **channel level** for intuitive understanding, as we were particularly interested in who formed the core of the network rather than the role of each video.
- As the recommendation algorithm of YouTube reflects the quality of video measured by user appreciation, personal preference, and diversity [40], it is logical that the channels at the network's core exert the most influence on information flow.
- Through k-core analysis and **multidimensional scaling** (MDS), we were able to determine the network core.
    - k-core is an index that identifies a highly cohesive region of the entire graph [47].
    - When the k-core property is combined with the MDS property that clusters network nodes with comparable relationships to other nodes, the k-core nodes tend to locate at the center of the network (ie, the core of network).
- As the majority of YouTube videos are viewed as a result of recommendations [44], the core of the recommendation network is the center of the information cascade in the dissemination of ... information.

Third, we investigated the network by examining the **ego networks** of institutions' channels, such as hospitals and news organizations, to see if they were in the core of the network.

- The ego network or egocentric network refers to "a network based on a particular individual...comprised of all the relations that a focal agent has with others" [47].
- We think the connection to news media and hospitals in the network is important, as trust in these institutions is related to the spread of misinformation [9].
- In addition, the news media serve as fact-checking institutions, and hospitals provide scientific health information to counter misinformation.
- Thus, a comparison of both institutions' ego networks can help us better comprehend and analyze the networking pattern between traditional media and YouTube viewing habits.

Results

YouTube Recommendation Network

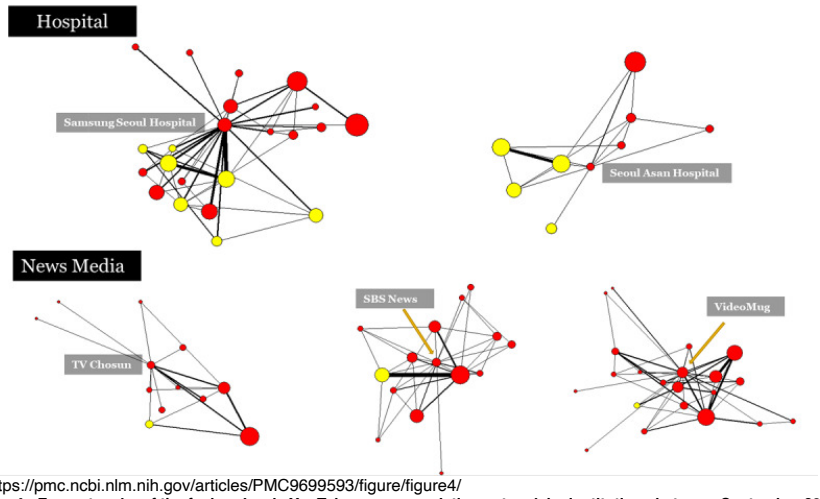


https://pmc.ncbi.nlm.nih.gov/articles/PMC9699593/#figure2

Fig. 3: Fenbendazole YouTube video recommendation network between September 2019 and February 2020.
The default node color is red.
The yellow nodes are the channels where fenbendazole self-administration was conducted.
The node size reflects the degree of a node, namely, the number of connections with other nodes.
The tie strength reflects the number of repeated recommendation linkages.

By contrast, the network of recommendations did not include any government or authoritative medical channels.

- Within the network core, there were two hospital channels;
  - however, it appears that the channels just mirrored users' YouTube viewing habits.
  - These channels did not include any content on fenbendazole.
  - In fact, these two hospitals are the top two hospitals in terms of the number of cancer patients they treat.
- News channels played no role in disseminating "true" pertinent information.



https://pmc.ncbi.nlm.nih.gov/articles/PMC9699593/figure/figure4/

Fig. 4: Ego networks of the fenbendazole YouTube recommendation network by institutions between September 2019 and February 2020.
The default node color is red. The yellow nodes are the channels where fenbendazole self-administration was conducted. The node size reflects the degree of a node, namely the number of connections with other nodes. The tie strength reflects the number of repeated recommendation linkages.

- The top two diagrams demonstrate how hospital channels were immediately connected to numerous video channels about self-administration of fenbendazole via a single recommendation, whereas
- news channels were rarely connected to these.

In other words, even if accurate information is distributed, patients and caregivers engaged in self-administration are unlikely to be connected to government and other authentic YouTube medical channels.

Principal Findings

This study delved into one of the cancer ... networks on YouTube. By analyzing the data from searched and recommended videos, we found that

- personal videos about self-administered fenbendazole were continuously uploaded and accumulated over time as if showing promising evidence for the use of fenbendazole as a cancer treatment.
- In addition, the recommended content network of fenbendazole has become the infrastructure for confirming the audience's belief and hope in fenbendazole as an alternative cancer medicine.
  - Patients are actively seeking health information over the internet, thereby increasing their self-efficacy in making treatment decisions and altering provider-patient interactions [49-52].
  - As such, the appearance of supportive professional videos stating that the use of fenbendazole for cancer is scientifically unknown, but possibly helpful, may inspire hope and belief among cancer patients and caregivers who are thinking about self-administering fenbendazole;
  - these videos may also lead patients and caregivers to disregard announcements from the National Cancer Center Korea and the Korean Medical Association.

Unfortunately, the effectiveness of fenbendazole has not been established, and other major adverse effects have been observed [53].

- During our investigation, we also found that the YouTube recommendation network was unrelated to credible medical knowledge content.
- Although some hospital channels were, indeed, connected to the network, it seemed to reflect people's viewing habits rather than topics related to fenbendazole.

In summary, while the YouTube content and recommendation network served as a substantial information source for complex contagion,

- medical institutions and government entities were excluded from the network, and no dialogue from them was discovered.

- This resulted in a breakdown of communication between patients and caregivers, resulting in enormous sales of fenbendazole tablets.
