

The Role of Social Network Services in Sharing Patient Experiences with the Wearable Cyborg Hybrid Assistive Limb

博士課程 ヘルスイノベーション研究科

62145001 : 長澤誠

研究指導教員 : 成松宏人

副研究指導教員 : 中村翔

I. Introduction

Sharing patient experiences is one of the most essential support resources for those suffering from their illness. Learning about the treatment experiences of others who have had similar experiences to one's own will promote health promotion behaviors(Campbell et al., 2004; Festinger, 1954; Helgeson & Cohen, 1996). Traditionally, face-to-face patient experience sharing has taken place, but in recent years, social networking services (SNS) have been used to share patient experiences(Setoyama et al., 2011). Patient experience sharing via social media and SNS is expected to become increasingly important in today's society, where direct patient interaction is complicated due to the global COVID-19 epidemic. Traditionally, information sharing has focused on text data(boyd & Ellison, 2007). However, with the spread of video SNS, it is now possible to share patient experiences intended to convey changes in movement, such as rehabilitation, in a way that is easy for viewers to understand. Many rehabilitation and other medical information videos have been uploaded on YouTube, a video SNS. They are being used as an educational tool and a place to share information on patient experiences(Azer et al., 2013; Madathil et al., 2015).

With the evolution of technology and the improvement of the internet environment, the use of social media worldwide is increasing. In 2023, there are estimated to be 4.89 billion total social media users worldwide(Social, 2023). It was found that YouTube is the second most actively used networking site after Facebook, boasting 2,562 million users in 2022. The impact of social networking sites, used by such a large number of users, on public health is significant. Various studies have highlighted the potential of social media as a tool for health interventions, supportive interactions among friends and family, users discussing their feelings, promoting healthy behavior changes and counseling, health campaigns, and medical education(Abroms, 2019). In contrast, negative public health effects of social media have also been observed. Issues such as offending or defaming people through the commenting function of social media present challenges(Kanchan & Gaidhane, 2023). Furthermore, the proliferation of misinformation, particularly regarding medical information, is a concern. The challenges lie in creating a system to guarantee the accuracy of information and in improving the information literacy of individuals who seek information independently.

In recent years, social media platforms have significantly expanded the avenues through which individuals can connect, offer and receive support, and share their experiences related to health and illness(Chou et al., 2009). Platforms such as Facebook have developed disease-specific support groups(Greene et al., 2011), and the

disease experience-sharing platform, PatientsLikeMe(Frost & Massagli, 2008)has been widely utilized. These online peer-to-peer networks are increasingly sought for informational and emotional support(Coursaris & Liu, 2009; Mo & Coulson, 2008). YouTube, in particular, has become a valuable resource for individuals with diverse health conditions(Chou et al., 2011; Frohlich & Zmyslinski-Seelig, 2012).

YouTube is the most commonly used video social network and is recognized as an essential online information source(de Bérail & Bungener, 2022; Madathil et al., 2015). Videos on rehabilitation and healthcare are also uploaded and used as a tool for sharing patient experiences and providing education(Azer et al., 2013). A distinctive feature of YouTube as an online information source is the diversity of narrative information it shares. The narrative content available on YouTube aids health communicators, practitioners, and researchers in understanding patient experiences from their perspectives(Chou et al., 2011). This insight suggests that clinicians could leverage this information to better comprehend patient viewpoints and provide more effective support(Charon, 2007). In addition, YouTube also features a commenting function, allowing for user discourse through text comments under individual videos(Eke et al., 2020).

YouTube enables anyone to post videos for free, and influencers who regularly upload videos to their personal YouTube channels are known as YouTubers(Jerslev, 2016). YouTubers significantly influence their viewers, and it has been reported that some people believe information obtained from their favorite YouTubers more than that obtained from their parents or friends(de Bérail & Bungener, 2022). Therefore, they are expected to be an effective source of health information.

In Japan, rehabilitation and exercise programs using robotic technology are attracting attention to extend the healthy life expectancy of older adults and reduce the burden on workers. One such program is the Hybrid Assistive Limb (HAL), a wearable cyborg. Although past research has shown the usefulness of HAL, the features of this device are not widely known because it has yet to be widely used(Kasai, 2019). How information about treatment with the new device can be made widely available to specialists and the general public, and how individuals can be given treatment options, is a significant challenge for the future of healthcare in Japan. One option to solve this issue is to share patient experiences through social networking services (SNS), where anyone can share their own experiences and research the experiences of others for free. We believe that the sharing of information on HAL, which until now has only reached a limited number of people, by actual users on how they feel about using HAL and its effects will increase opportunities for professionals and the general public to obtain information and will lead to more treatment options. Exercise programs using HAL contain information that is difficult to explain in writing, such as how HAL assists body movements and how movements such as standing and walking change before and after the HAL exercise program. Therefore, YouTube, which enables the sharing of this information, can be an essential source of information for patients who desire to undergo HAL treatment in the future.

HAL-related videos are uploaded on YouTube, and a variety of content is shared, including patient experiences and conversations among patients. Thus, various HAL-related videos are shared on YouTube, and the number of views varies from tens of thousands to almost nothing. Previous research focusing on health-related information on YouTube has assessed multiple aspects of the videos, including their contents and the quality of the information presented(Toussaint et al., 2022). Among these, videos featuring users sharing their perspectives and experiences have been shown to attract a higher number of views(Lee et al., 2021; Madathil et al., 2015). This trend has gradually elucidated the type of content YouTube viewers are interested in. However, there has been a lack of research evaluating HAL-related videos on YouTube. Consequently, the nature of information sought by YouTube viewers in HAL-related content and their usage patterns remain unclear. To understand the HAL-related information viewers seek, it is essential to identify the characteristics of the most frequently viewed HAL-related videos. We hypothesize that HAL-related videos on YouTube, similar to general health-related information videos, exhibit specific characteristics that correlate with higher viewership.

In this study, we aimed to analyze the content and quality of HAL-related videos viewed by various people to

clarify the content required by YouTube viewers. The study promotes the creation of videos based on the results of this study, increasing the number of HAL-related YouTube videos viewed. This will help satisfy the information needs of patients currently undergoing HAL treatment, those considering undergoing HAL treatment in the future, and their family members.

II. Characteristics of the most viewed Hybrid Assistive Limb-related videos on YouTube

We searched for YouTube videos using five keywords. The keywords “Robot suit HAL,” “Cyberdyne HAL,” “HAL walk,” and “Rehabilitation HAL” were extracted from the Google Keyword Planner. “Wearable cyborg HAL” was also used as a keyword. The top 50 most viewed videos searched for every five keywords were extracted. A total of 250 videos with the highest number of views were identified. A YouTube search was conducted on October 27, 2021. (1) Rehabilitation-related videos using HAL and (2) Japanese language were included. Meanwhile, (1) non-Japanese language videos, (2) duplicate videos, (3) videos with rough quality and audio, (4) HAL-related videos explained for purposes other than rehabilitation, and (5) videos that were illegal copies of TV programs were excluded. Of the 250 videos, 116 were excluded (two non-Japanese videos, 54 duplicate videos, 3 with rough quality and audio, 55 HAL-related videos explained for purposes other than rehabilitation, and two illegal video copies of TV programs). We extracted the top 100 videos. The video title, number of views, upload date, uploader name, video length, number of days since the upload, information contained in the video, comments recorded on the videos, and comments from viewers were obtained. The videos were categorized into four groups based on the contents: (1) training, defined as video recordings of patient experience during HAL training; (2) advertisement, defined as video recordings of advertisements on HAL-related initiatives; (3) lecture, defined as video recordings of lectures about HAL; and (4) review, defined as video recordings of patient experience after HAL training. The videos were categorized into five groups based on the uploader: (1) YouTuber, defined as HAL users with more than 1,000 subscribers on the YouTube channel; (2) regular creator, defined as HAL users with less than 1,000 subscribers on the YouTube channel; (3) company, defined as the video uploaded by the company; (4) hospital, defined as the video uploaded by the hospital; and (5) municipality, defined as the video uploaded by the municipality. DISCERN was used to evaluate the quality of videos, designed to help users of consumer health information judge the quality of written information related to treatment choices (Charnock et al., 1999). One physical therapist and one physician independently rated the quality of each video, and the average of the two scores was used in the analysis. Comments from viewers, presumed to have illnesses or disabilities based on the content of their comments, were collected. This collection also included critical remarks. The retrieval of these comments from viewers was conducted on December 19, 2023. As supplemental data, the content information of YouTube videos related to virtual reality was obtained in the order of the number of views. The search keyword used was VR rehabilitation. The content was retrieved: The video title, number of views, source, like count, and comment count. The videos were also categorized into five groups based on the source: (1) YouTubers, defined with more than 1,000 subscribers on the YouTube channel; (2) Regular creators, defined with less than 1,000 subscribers on the YouTube channel; (3) Company, defined as the video uploaded by the company; (4) Hospital, defined as the video uploaded by the hospital; and (5) University/Collage, defined as the video uploaded by the University or Collage. Content information for the YouTube video on virtual reality was retrieved on December 19, 2024.

Descriptive statistics were calculated to characterize the following data: video title, number of views, upload date, uploader name, video length, number of days since the upload, DISCERN score and the main content of the acquired video lists. Videos uploaded by YouTubers and those uploaded by other uploaders were compared using the Wilcoxon rank-sum test. Statistical analyses were performed using R software (version 1.4.1106, R Foundation for Statistical Computing, Vienna, Austria). A P value of <.05 was considered significant.

The results of this study indicate that among 100 analyzed videos, the most shared content was the training

videos on HAL (n=58). The most common uploaders of videos were users (YouTubers and regular creators) (n=68), followed by companies (n=25), hospitals (n=5), and municipalities (n=2). Of the 100 HAL videos, 76 were uploaded from 2016 to 2021 and 24 were uploaded from 2009 to 2015. The videos uploaded by YouTubers had a significantly higher number of views than those uploaded by other uploaders (YouTuber vs. Others: median 18,329 (range: 853–4,090,031) vs. 2,286 (range: 882–133,697); $P < .001$). Furthermore, they had significantly higher DISCERN16 scores, which serves as the basis for the overall evaluation of the publication's overall quality (YouTuber vs. others: median 3 (range: 1–5) vs. 1 (range: 1–4); $P < .001$). The HAL-related videos analyzed in this study elicited comments from viewers with illnesses or disabilities. Such comments were notably absent in videos from Regular creators and Hospitals. Although only a portion of the comments on YouTuber videos was obtained for this study, a higher proportion of these comments came from viewers with illnesses or disabilities compared to other sources. Conversely, YouTuber videos also attracted critical comments about the YouTubers themselves. The results of supplemental data analysis indicate that the most viewed YouTube videos concerning Virtual Reality Rehabilitation garnered a total of 6,710 views. Regarding source popularity, companies were the predominant creators, accounting for 61% of the total (22/36 videos). Universities or colleges contributed to 14% (5/36 videos), YouTubers to 11% (4/36 videos), regular creators to 8% (3/36 videos), and hospitals to 6% (2/36 videos) of the content.

III. Conclusion

Our study is the first study to analyze HAL-related YouTube videos. This study contributes to understanding the information about HAL, which is widely viewed on YouTube. Our results showed that the most popular HAL-related videos were primarily uploaded by users, and the most viewed content was videos of training situations. Information on training using HAL on YouTube is valuable to the general public; sharing patient experiences on YouTube may satisfy the public's information acquisition needs. Furthermore, it was found that YouTuber videos exert more influence than those created by hospitals or corporations. Collaborating with YouTubers might be a practical approach to disseminating valuable but underutilized medical technologies, such as Virtual Reality and the Metaverse. In the future study, we want to investigate how HAL-related YouTube videos influence patients' treatment choices.

IV. References

- Abroms, L. C. (2019). Public Health in the Era of Social Media. *Am J Public Health*, 109(S2), S130-s131. <https://doi.org/10.2105/ajph.2018.304947>
- Azer, S. A., Algrain, H. A., AlKhelaif, R. A., & AlEshaiwi, S. M. (2013). Evaluation of the educational value of YouTube videos about physical examination of the cardiovascular and respiratory systems. *J Med Internet Res*, 15(11), e241. <https://doi.org/10.2196/jmir.2728>
- boyd, d. m., & Ellison, N. B. (2007). Social Network Sites: Definition, History, and Scholarship. *Journal of Computer-Mediated Communication*, 13(1), 210-230. <https://doi.org/10.1111/j.1083-6101.2007.00393.x>
- Campbell, H. S., Phaneuf, M. R., & Deane, K. (2004). Cancer peer support programs-do they work? *Patient Educ Couns*, 55(1), 3-15. <https://doi.org/10.1016/j.pec.2003.10.001>
- Charnock, D., Shepperd, S., Needham, G., & Gann, R. (1999). DISCERN: an instrument for judging the quality of written consumer health information on treatment choices. *J Epidemiol Community Health*, 53(2), 105-111. <https://doi.org/10.1136/jech.53.2.105>
- Charon, R. (2007). What to do with stories: the sciences of narrative medicine. *Can Fam Physician*, 53(8), 1265-1267.

- Chou, W.-Y. S., Hunt, Y., Folkers, A., & Augustson, E. (2011). Cancer Survivorship in the Age of YouTube and Social Media: A Narrative Analysis [Original Paper]. *J Med Internet Res*, 13(1), e7. <https://doi.org/10.2196/jmir.1569>
- Chou, W.-y. S., Hunt, Y. M., Beckjord, E. B., Moser, R. P., & Hesse, B. W. (2009). Social Media Use in the United States: Implications for Health Communication [Original Paper]. *J Med Internet Res*, 11(4), e48. <https://doi.org/10.2196/jmir.1249>
- Coursaris, C. K., & Liu, M. (2009). An analysis of social support exchanges in online HIV/AIDS self-help groups. *Computers in Human Behavior*, 25(4), 911-918. <https://doi.org/https://doi.org/10.1016/j.chb.2009.03.006>
- de Bérail, P., & Bungener, C. (2022). Favorite YouTubers as a source of health information during quarantine: viewers trust their favorite YouTubers with health information. *Soc Netw Anal Min*, 12(1), 88. <https://doi.org/10.1007/s13278-022-00925-5>
- Eke, R., Li, T., Bond, K., Ho, A., & Graves, L. (2020). Viewing Trends and Users' Perceptions of the Effect of Sleep-Aiding Music on YouTube: Quantification and Thematic Content Analysis. *J Med Internet Res*, 22(8), e15697. <https://doi.org/10.2196/15697>
- Festinger, L. (1954). A theory of social comparison processes. *Human Relations*, 7, 117-140. <https://doi.org/10.1177/001872675400700202>
- Frohlich, D. O., & Zmyslinski-Seelig, A. (2012). The Presence of Social Support Messages on YouTube Videos About Inflammatory Bowel Disease and Ostomies. *Health Communication*, 27(5), 421-428. <https://doi.org/10.1080/10410236.2011.606524>
- Frost, J. H., & Massagli, M. P. (2008). Social Uses of Personal Health Information Within PatientsLikeMe, an Online Patient Community: What Can Happen When Patients Have Access to One Another's Data [Original Paper]. *J Med Internet Res*, 10(3), e15. <https://doi.org/10.2196/jmir.1053>
- Greene, J. A., Choudhry, N. K., Kilabuk, E., & Shrank, W. H. (2011). Online social networking by patients with diabetes: a qualitative evaluation of communication with Facebook. *J Gen Intern Med*, 26(3), 287-292. <https://doi.org/10.1007/s11606-010-1526-3>
- Helgeson, V. S., & Cohen, S. (1996). Social support and adjustment to cancer: reconciling descriptive, correlational, and intervention research. *Health Psychol*, 15(2), 135-148. <https://doi.org/10.1037//0278-6133.15.2.135>
- Jerslev, A. (2016). In The Time of the Microcelebrity Celebrification and the YouTuber Zoella. *International Journal of Communication*, 10, 5233-5251.
- Kanchan, S., & Gaidhane, A. (2023). Social Media Role and Its Impact on Public Health: A Narrative Review. *Cureus*, 15(1), e33737. <https://doi.org/10.7759/cureus.33737>
- Kasai, F. (2019). Awareness Survey on Wearable Walking Assistance Robots. *The Japanese Journal of Rehabilitation Medicine*, 56(3), 242-248. <https://doi.org/10.2490/jjrmc.18007>
- Lee, K. N., Joo, Y. J., Choi, S. Y., Park, S. T., Lee, K. Y., Kim, Y., & Son, G. H. (2021). Content Analysis and Quality Evaluation of Cesarean Delivery-Related Videos on YouTube: Cross-sectional Study. *J Med Internet Res*, 23(7), e24994. <https://doi.org/10.2196/24994>
- Madathil, K. C., Rivera-Rodriguez, A. J., Greenstein, J. S., & Gramopadhye, A. K. (2015). Healthcare information on YouTube: A systematic review. *Health Informatics J*, 21(3), 173-194. <https://doi.org/10.1177/1460458213512220>
- Mo, P. K. H., & Coulson, N. S. (2008). Exploring the Communication of Social Support within Virtual Communities: A Content Analysis of Messages Posted to an Online HIV/AIDS Support Group. *CyberPsychology & Behavior*, 11(3), 371-374. <https://doi.org/10.1089/cpb.2007.0118>
- Setoyama, Y., Yamazaki, Y., & Namayama, K. (2011). Benefits of peer support in online Japanese breast cancer communities: differences between lurkers and posters. *J Med Internet Res*, 13(4), e122.

<https://doi.org/10.2196/jmir.1696>

Social, S. (2023). *50+ of the most important social media marketing statistics for 2023*. Retrieved 6 January from <https://sproutsocial.com/insights/social-media-statistics/>

Toussaint, P. A., Renner, M., Lins, S., Thiebes, S., & Sunyaev, A. (2022). Direct-to-Consumer Genetic Testing on Social Media: Topic Modeling and Sentiment Analysis of YouTube Users' Comments [Original Paper]. *JMIR Infodemiology*, 2(2), e38749. <https://doi.org/10.2196/38749>